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The development and validation of the Diagnosis Impact Scale (DIS) a self-report measure of the effect of psychiatric diagnoses on recipients

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The Development and Validation of the Diagnosis Impact Scale (DIS): A Self-Report Measure of the Effect of Psychiatric Diagnoses on Recipients

By

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Abstract

Background: Despite the dominance of psychiatric diagnosis within mental healthcare systems, there is no validated measure of diagnosis impact on those who receive them. Consequently, there is also a paucity of statistically generalisable research on the experience of receiving and living with a diagnosis.

Aims: To develop a valid and reliable measure of the effect of psychiatric diagnosis on recipients, the Diagnosis Impact Scale (DIS), for clinical and research use.

Method: Measure development protocols used included the generation of an item pool, expert rating of items, and Three Step Test Interviews. Psychometric properties of the DIS were investigated, including internal consistency, convergent validity, discriminant validity, and criterion validity. A principal components analysis was carried out on a sample of 248 people with psychiatric diagnoses, followed by a two-parameter IRT analysis.

Findings: The principal components analysis suggested that the 19-item DIS had two discrete subscales: Helpfulness of Diagnosis and Diagnosis-Related Self-Stigma. Each displayed excellent reliability in this sample, with Cronbach's alphas of 0.93 (n=256) and 0.81 (n=263) for Helpfulness of Diagnosis and Diagnosis-Related Self-Stigma respectively. They were also found to have acceptable content and construct validity. Significant associations were found between both subscales and diagnosis type, perceived correct diagnosis, receipt of treatment due to diagnosis, and helpfulness of said treatment. Helpfulness of Diagnosis was significantly associated with age and time since diagnosis. Diagnosis-Related Self-Stigma was significantly associated with having multiple diagnoses, the number of these, and the type of healthcare professional who gave the diagnosis (e.g. GP or psychiatrist). The two-parameter IRT analysis showed

that both subscales were within acceptable ranges for discrimination and differentiation between strength of attitude.

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Chapter 1:
Introduction

1.1. Introduction to Psychiatric Diagnosis

1.1.1. Definition of psychiatric diagnosis.

Despite the substantial interest in psychiatric diagnosis in recent years, a widely-used definition of the construct is elusive. This raises questions about the scope of psychiatric diagnosis as a concept and what constitutes a diagnosis or a diagnostic process per se. In terms of research, the lack of a working definition creates challenges for replicability and comparison of studies on diagnosis. For the purposes of this thesis, it may be helpful to also consider broader definitions.

The Oxford English Dictionary Online defines diagnosis as 'the identification of the nature of an illness or other problem by examination of the symptoms' (Diagnosis, 2019). Double (2002) defines diagnosis as 'the art or act of identifying a disease from its symptoms and signs' (p.1) but he also refers to a broader definition 'the analysis of the cause or nature of a condition, situation or problem' (p.1) . In a text on psychiatric nursing, Fortinash and Holoday Worret (2000) define diagnosis as 'the categorisation and description of mental disorders'. A service-user leaflet by the British Psychological Society, hereafter BPS, Division of Clinical Psychology defines a psychiatric diagnosis as 'a medical term used to describe patterns of experiences or behaviours that may be causing distress and/or be seen as difficult to understand' (BPS, 2016, p. 2). The broader definitions above are more relevant to physical diagnosis as they use medical terms like 'illness', 'disease', 'nature', and 'signs' while the last two definitions better capture the descriptive function of psychiatric diagnosis as distinct from the often explanatory function diagnosis often has in physical medicine (Heckers, 2015; Krystal & State, 2014; Dean & Murray, 2003; Weiste, Peryakyla, Valkeapaa, Savander, & Hintikka,

2018). There is a need for a more widely-used and accepted definition of psychiatric diagnosis as a concept which is distinct from physical diagnosis in terms of the processes involved which do not involve assessment of 'signs' and its limitations in terms of explanation and causation (Frances & Egger, 1999; Timimi, 2014). The lack of a popular definition of psychiatric diagnosis implies that it is synonymous with diagnosis in physical medicine while it is acknowledged by many experts to be quite different to it (Bracken et al., 2012; Coulter, 1979; Dean & Murray, 2003; Moncrieff, 2010; Weiste et al., 2018).

1.1.2. History of psychiatric classification and diagnosis.

Early psychiatric classification is thought to date back to Ancient Greece (Harris, 2013). However, the current system is often linked to psychiatrist Emil Kraepelin. His was the first classification to group disorders by symptom patterns, course and outcome, rather than focusing on a major symptom similarity or positing a specific aetiological explanation (Jablenski, 2007). Kraepelin believed that, as in physical medicine, psychiatric disorders were separate natural kinds with a biological and genetic basis, the existence of which could be proven using extensive longitudinal data (Bentall, 2003; Decker, 2007; Pilgrim, 2007). He is best-known for distinguishing between dementia praecox and manic-depressive illness (Bentall, 2003). Campbell (2007) suggests that the use of diagnosis and classification systems like Kraepelin's were instrumental in the medicalisation of mental health treatment in asylums which had previously been the purview of non-medics.

Kraepelin was succeeded by Karl Jaspers, who wrote the highly influential *Allgemeine Psychopathologie [General Psychopathology]* (Jaspers, 1913), a critique of psychiatric practices of the time and proposal of an alternative paradigm. Jaspers believed that psychiatric disorders should be diagnosed based on form rather than

content, with symptom information being gathered using the 'biographical method' where biographical details and subjective patient accounts of their experiences were prioritised. See Jablenski (2013) for further details.

In the 1940s, psychoanalytic theory became dominant in psychiatry, a trend which continued for about twenty years. This included a shift in attention to the idiographic rather than the nomothetic and the popularization of ideas pertaining to unconscious and psychological origins of psychiatric disturbance rather than biological or neurological ones (Suris, Holliday, & North, 2016). As a profession, psychiatry came under threat from the anti-psychiatry movement in the 1960s and 1970s (Dean & Murray, 2003; Double, 2002) with experiments by American psychologist David Rosenhan being particularly influential (Rosenhan, 1973). His famous paper, On Being Sane in Insane Places, suggested the inability of psychiatrists to distinguish between those who were well and those who were psychiatrically ill. This, and his subsequent reliability and validity experiments caused widespread questioning of psychiatry as a profession. Simultaneously, Robins and Guze began a movement to develop a research-based nosology with a strong emphasis on validity. They viewed the existing system as lacking uniformity and too reliant on clinical judgement (Robins & Guze, 1970). In 1972, they published a diagnostic classification manual known as the 'Feighner criteria' (Feighner, Robins, Guze, Woodruff, Winokur, & Munoz, 1972).

There was also a renewed focus on and push to increase the reliability of diagnosis during this period whereby a patient would be diagnosed with the same disorder by multiple or ideally all psychiatrists (Dean & Murray, 2003; Moncrieff, 2010;). Clear criteria were devised for each disorder which had to be satisfied prior to diagnosis (Frances, 2013). The revised criteria were contained in the Diagnostic and Statistical Manual of Mental Disorders III (DSM-III) published by the American

Psychiatric Association (APA) in 1980 and used in the United States as well as the International Classification of Diseases 9 (ICD 9), published by the World Health Organization (WHO) in 1979 and used more widely across the world. The anti-psychiatry movement precipitated a significant expansion of both classifications, with DSM going from 128 disorders in 1952 upon initial publication, to 228 in 1980 (Blashfield, Keeley, Flanagan, & Miles, 2014; Moncrieff, 2010). Similarly, the psychiatric disorders chapter of the ICD expanded from about 30 to 100 categories during this time (Laird, Smith, Dutu, & Mellsop, 2009; Sartorius, 1988). Some authors have argued that psychiatry became more medicalised and aligned with neuropathology as a reaction to challenges in the 1960s and 1970s (Double, 2002). Georgaca (2013) suggests that the increased emphasis on manualisation and criteria was psychiatry's attempt to regain credibility by adopting a stronger, more 'scientific' discourse associated with general medicine.

More recently, the concept of psychiatric diagnosis received renewed interest before the publication of DSM-5 in 2013 (Callard, 2014; Craddock & Mynors-Wallis, 2014; Frances, 2013). Many critics (including, Allen Frances, the chair of the DSM-IV taskforce) felt that the revisions broadened the scope of diagnosis and thus medicalised 'problems with living' which were part of normal human experience (Frances, 2013; Frances & Widiger, 2012). As the classification of mental health problems has expanded in recent decades, the public's reaction has also intensified, most significantly that of mental health service users. Although the service user movement in mental health dates back to the 17th century (Campbell, 2009), it gathered considerable momentum during the anti-psychiatry era and has been growing since. The service user perspective is now recognised as an integral part of discussions on and decisions about mental health (Magliano, Fiorillo, Malangone, Del Vecchio, Maj & the Users' Opinions

Questionnaire Working Group, 2008). People who have experienced the mental healthcare system as 'consumers' are involved in research, development of treatments, service development more generally, clinical training and policy-making (Bracken et al., 2012; Campbell, 2007; Milton & Mullan, 2015).

1.1.3. Diagnostic classifications.

The standardisation of psychiatric diagnosis following the anti-psychiatry movement in the 1960s and '70s led to increased focus on categories, criteria and classifications which have come to dominate mental healthcare (Moncrieff, 2010). Historically, there were many diagnostic classifications in use simultaneously both inter- and intra-nationally (Sartorius, 1988; Suris, Holliday, & North, 2017). Sartorius (1988) refers to numerous countries with their own taxonomies, some quite comprehensive, he cites the then USSR as a notable example. However, in recent decades, two very dominant classifications have emerged. Globally, the most prominent diagnostic manuals in psychiatry are the Diagnostic and Statistical Manual of Mental Disorders (DSM) and the Mental, Behavioural, and Neurodevelopmental Disorders section of the International Classification of Diseases (ICD), published by the APA and the WHO respectively. The DSM and ICD provide guidance for practitioners on the identification and diagnosis of mental disorders in addition to serving as a framework for research and public policy. The DSM is now in its fifth edition, released in 2013 while ICD-11 was released in June 2018 (APA, 2013; WHO, 2018).

DSM-5 consists of three sections, the second of which gives a comprehensive list of disorders (grouped into 21 categories) with descriptions and criteria for each. In ICD-11 (WHO, 2018), which contains both physical and mental disorders, Chapter 6 of ICD-11 entitled Mental, Behavioural, or Neurodevelopmental Disorders, like DSM-5, consists of 21 categories of mental disorder. Both DSM-5 and ICD-11 were developed

as revised editions of previous classifications by task-forces including healthcare professionals, scientists, service users, and family stakeholders (APA, 13; WHO, 2018). A survey of 205 psychiatrists across 66 countries found that, when previous versions of the classifications were compared, globally ICD-10 was the preferred manual for clinical training and practice, while DSM-IV was dominated in the United States and Canada (Mezzich, 2002).

ICD-11 describes the disorders in Chapter 6:

> Mental, behavioural and neurodevelopmental disorders are syndromes characterized by clinically significant disturbance in an individual's cognition, emotional regulation, or behaviour that reflects a dysfunction in the psychological, biological, or developmental processes that underlie mental and behavioural functioning. These disturbances are usually associated with distress or impairment in personal, family, social, educational, occupational, or other important areas of functioning. (WHO, 2018, "Description", para. 1)

The first two elements of the DSM-5 definition of 'mental disorder' are almost identical to the above:

> A mental disorder is a syndrome characterized by clinically significant disturbance in an individual's cognition, emotion regulation, or behavior that reflects a dysfunction in the psychological biological, or developmental processes underlying mental functioning. Mental disorders are usually associated with significant distress or disability in social, occupational, or other important activities. An expectable or culturally approved response to a common stressor or loss, such as the death of a loved one, is not a mental disorder. Socially deviant behavior (e.g. political, religious, or sexual) and conflicts that are primarily between the individual and society are not mental disorders unless

> the deviance or conflict results from a dysfunction in the individual, as described above. (APA, 2013, p. 20)

However, the third and fourth elements of the DSM-5 definition add criteria to exclude natural human responses to adversity and non-pathological counter-normative behaviour. The similarity between the definitions is an example of significant harmonisation efforts made by the developers of both manuals, including the elimination of the multiaxial system of previous DSM manuals in DSM-5 which increased its similarity to ICD-11 (Clark, Cuthbert, Lewis-Fernandez, Narrow, & Reed, 2017). However, some significant divergence remains, such as the removal of 'gender incongruence' from Chapter 6 of ICD-11 while 'gender dysphoria' is included in DSM-5 (Evans et al., 2017).

1.1.4. Psychiatric diagnosis: the current context.

Francis (2013) expresses concern about the 'over-inclusiveness' of recent classifications and the rapid increase in diagnosis of some disorders in the past twenty years. This expansion of diagnosis is thought to be responsible for a rise in the number of people taking psychotropic medication (Bracken et al., 2012) without a corresponding improvement in mental wellbeing (Bentall, 2013; Johnstone & Boyle, 2018; Moncrieff, 2007; Timimi, 2014).

In 2014, the Adult Psychiatric Morbidity Survey (Stansfeld et al., 2016) found that in the UK, one in six adults reported symptoms consistent with a Common Mental Disorder (CMD) with women being more likely to be affected (one in five) than men (one in eight). Almost half of adults surveyed believed they met criteria for a mental health diagnosis at some point in their lives with a third of these receiving confirmation from a clinician. 13.7% of those surveyed had received a mental health diagnosis in the year prior to the study. According to the Institute of Health Metrics and Evaluation

(IMHE), the global adult prevalence of mental health and substance user disorders was 15.5% in 2016 (IMHE, 2017). However, it is not clear whether all individuals received an official diagnosis. According to WHO Global Health Estimates (2017), regarding 'common mental disorders' (recent information pertaining to global prevalence of all mental disorders has not been published), in 2015 there was a global prevalence rate of 4.4% for depression and 3.6% for anxiety. Prevalence of both disorder groups was higher for females than males.

Diagnosis is frequently sought for practical reasons, particularly to access treatment. In the United Kingdom, a formal diagnosis is often a prerequisite for treatment within the public healthcare system (Fletcher, 2012; BPS, 2016). In the United States, insurance companies require an official diagnosis in order to fund mental health treatment (Davies, 2013). Despite the apparent increasing prevalence of mental health diagnosis, there are some significant developments which suggest that it may be losing favour. In 2013, the BPS Division of Clinical Psychology, which has over 10,500 members, released a position statement opposing current diagnostic systems. In this position statement, the authors argue that the current psychiatric diagnosis framework fails to acknowledge or explicate the association between contextual adversities (social, familial, and cultural) and mental health issues thereby implying a fault or deficit in the individual (BPS, 2013). Some other opponents of psychiatric diagnosis have suggested that its survival despite significant inadequacies is in part due to the relative simplicity, from a political and policy-making perspective, of adhering to a medical model of psychological distress which locates the problem within the individual compared to addressing the many societal problems which give rise to it (Moncrieff, 2010; Pilgrim, 2013). Additionally, a large service-user organisation in the UK, the Hearing Voices Network (HVN), released a position statement challenging DSM-5 and psychiatric

diagnosis (HVN, 2013). This rejection of diagnosis is due to the perceived over-medicalisation of psychological distress without a corresponding increase in levels of mental wellbeing and the continued lack of empirical evidence to support the current diagnostic system (see Academic Debates on Psychiatric Diagnosis for further discussion).

1.2. Academic Debates on Psychiatric Diagnosis

In this section I will present some of the most frequently cited topics and arguments found in opinion articles on psychiatric diagnosis. It should be noted that due to the focus on service-user perspective and limitations on the length of this thesis, a comprehensive coverage of debates on this polemic topic is not possible. However, I have suggested further publications that cover the debates on this below.[1]Regardless of stance on diagnosis, the vast majority of authors agree that diagnosis has a profound effect on recipients/service-users (Abbott, Bernard, & Forge, 2012; Bjorklund, 1996; Callard, 2014; Craddock, Kerr, & Thapar, 2010; Howlin & Moore, 1997; Laird, Smith, Dutu, & Mellsop, 2009; Moniz-Cook & Woods, 1997; Parker, Graham, Fletcher, Futeran, & Friend, 2014; Rose & Thornicroft, 2010) and how psychological distress is viewed in society (Bracken et al., 2012; Brown, 1995; Cromby, Harper, & Reavey, 2007; Georgaca, 2013; Maddux, 2016; Moncrieff, 2010). Moncrieff (2010) maintains that diagnosis has huge power in terms of treatment selection and adherence, she

[1] For further delineation of the anti-diagnosis arguments, clinical psychologist Lucy Johnstone, provides a thorough and accessible account in A Straight-Talking Introduction to Psychiatric Diagnosis. Although it is aimed at service-users, it covers the topic quite comprehensively and succinctly. Also anti-diagnosis but more focused on the development and dominance of the DSM, is James Davies' Cracked: Why Psychiatry is Doing More Harm Than Good. Stijn Vanheule takes a more moderate, yet critical stance on diagnosis in Psychiatric Diagnosis Revisited: From DSM to Clinical Case Formulation. Other current and prolific authors on this side of the debate include Joanna Moncrieff, Sammi Timimi, David Pilgrim, Mary Boyle, John Read, and Richard Bentall. Conversely, authors who write in support of diagnosis include Anthony David, Norman Sartorius, Nick Craddock, Laurence Mynors-Wallace, and Stephen Heckers. Apart from psychiatry textbooks, there do not seem to be substantial texts written from the pro-diagnosis point of view. This is likely to reflect the dominance of psychiatric diagnosis while those who oppose it represent a movement against the status quo and therefore endeavour to generate support.

proposes that it carries such weight that the treatments which are indicated by diagnoses are perceived to be the only option. Some authors question how psychiatric diagnosis has endured despite, as they see it, substantial and legitimate criticism (Cromby et al., 2007; Pilgrim, 2000). Similarly, Dean and Murray (2003) query whether the longevity of the term 'schizophrenia' is testament to the marketing capacity of the America Psychiatric Association or its usefulness to service users.

Conversely, some authors point out a gradual movement away from diagnosis. Manderscheid et al. (2010) suggest that diagnosis is featuring less in definitions of mental illness. Timimi (2014) and Johnstone (2014) note a distancing from diagnostic categories by major research bodies such as the National Institute for Mental Health (NIMH). Additionally, Boyle (2007) references clinical psychology's theoretical and clinical departure from diagnosis.

Psychiatric diagnosis remains quite a controversial topic, with professionals divided on its usefulness in clinical work. As diagnosis remains part of the dominant culture in mental health care and represents the status quo, the majority of theoretical and opinion literature on this theme is critical, however there are some articles, mentioned below, which defend diagnosis.

1.2.1. Reliability.

Psychiatric diagnosis has been criticised by academics as it is thought to lack reliability (Callard, Bracken, David, & Sartorius, 2013). The fact that a service user can receive different diagnoses depending on the treating clinician is seen as indicative of low inter-rater reliability. Similarly, while one clinician giving multiple diagnoses to the same service-user over time is linked to low test-retest reliability (Pilgrim, 2016). Johnstone (2014) stresses the low reliability rates associated with psychiatric diagnosis. On the other hand, Craddock and Mynors-Wallis (2014) claim that due to diagnostic

criteria, psychiatric diagnosis is similarly reliable to that in physical medicine if it did not have diagnostic tests. However, the reality is that there are diagnostic tests in physical medicine which make it reliable. Timimi (2014) argues that reliability has been forced upon psychiatric diagnosis, where it would not otherwise be evident, by developing criteria for disorders. Again, this feels like criticising something for having defined its terms. The reliability of diagnosis was greatly increased with the release of DSM III in 1980 (APA, 1980), when lists of criteria for diagnoses were published in place of definitions. Some authors point out the futility of being able to reliably diagnose something which they see as lacking validity (Johnstone, 2014).

1.2.2. Validity.

In terms of psychiatric disorders, validity is 'the extent to which it represents a naturally occurring category' (Timimi, 2014, p. 209). The validity of psychiatric disorder categories is often challenged, with some feeling it has been neglected due to an excessive focus on reliability (Moncrieff, 2010; Parnas, 1994). Many authors highlight the lack of evidence for diagnostic categories and are therefore sceptical of the notion that these are naturally occurring entities (Bentall, 2009; Boyle, 2007; Brockington, 1992; Kotov et al., 2011; Krystal & State, 2014: Sartorius, 1988; Timimi, 2014). Some note the heterogeneity of symptoms among people with the same diagnosis as well as the overlap in symptoms between those with different diagnoses (Bentall, 2009; Boyle, 2007). The lack of diagnosis stability is often referred to in critiques of classification; prevalent comorbidity, multiple diagnoses and changing diagnoses have been seen by some as evidence of poor validity of categories (Bentall, 2009; Timimi, 2014).

The expansion of diagnostic classifications is sometimes used to question the validity of diagnosis i.e. if the categories are naturally occurring entities, how can so

many more arise in such a short space of time? Frances (2013) criticised the proposals for DSM 5, arguing that the changes would mean that psychologically well individuals would meet criteria for mental disorders. On the other hand, Craddock and Mynors-Wallis (2014) argue that changes and developments in classifications do not negate their validity given that this is also seen in general medicine.

1.2.3. Evidence for diagnostic categories.

Many authors argue that there is no compelling evidence to support the pathophysiological explanation for mental health difficulties (Boyle & Johnstone, 2014; Bracken et al., 2012; Double, 2002; Heckers, 2015; Kapur, Mizrahi, & Li, 2005; Moncrieff, 2007; Moncrieff, 2010; Rose & Thornicroft; 2010, Timimi, 2014;) and some conclude that the framing of mental health issues as biologically based or attributing them to an underlying disease equates to denying the evidence base (Bentall, 2009; Bracken et al., 2012; Boyle, 1990).

There are currently no physical tests for mental disorders with the exception of some neuropsychiatric conditions (Heckers, 2015; Dean & Murray, 2003; Timimi, 2014; Weiste et al., 2018). Consequently, the subjectivity of psychiatric diagnosis is highlighted by several authors, both opponents of diagnosis and those who remain neutral (Boyle, 2007; Frances, 2013; Dean & Murray, 2003; Timimi, 2014). Conversely, North and Suris (2017) state that psychiatric diagnosis is based on 'a conceptual paradigm that is empirically-based, atheoretical, and agnostic toward etiology' (p. 3). Some criticise the continued investment in research on biomarkers at the expense of pursuing psychosocial research and other avenues (Bentall, 2009; Bracken et al., 2012; Timimi, 2014) while others call for increased genetic and biological research (Heckers, 2015). Frances (2013) proposes that the continued search

for a biological basis for mental health problems is in part driven by the pharmaceutical companies who stand to benefit significantly from such a discovery.

1.3. Alternatives to Diagnosis

In this section, I will outline ways of thinking about psychological distress, empirical and clinical, which do not involve diagnosis. As seen below, some approaches to mental health have been conceptually incongruent with diagnosis from their inception while other examples are new developments that represent a response to diagnosis and traditional classification of mental health problems.

1.3.1. Person-centred therapy.

Diagnosis is not central to all therapeutic modalities. In fact, some approaches, such as person-centred therapy, oppose the categorisation of distress by the therapist as they view the client as the expert on their difficulties (Gillon, 2013). Rogers (1951) states 'In a very meaningful way therapy is diagnosis, and this diagnosis is a process which goes on in the experience of the client, rather than in the intellect of the clinician' (p. 22). In a critique of diagnosis from a person-centred perspective, Merry (1999) argues that focus on pathology can mean that both client and therapist devalue their respective strengths. Instead, person-centred therapy employs a collaborative assessment model where the feasibility of the therapy is considered, with both parties acting as assessors (Wilkins & Gill, 2003).

1.3.2. The Psychodynamic Diagnostic Manual.

The Psychodynamic Diagnostic Manual (PDM) was developed by a number of psychoanalytic and psychodynamic bodies as an addition to the DSM and ICD rather than a competing nosology. It is primarily intended as a clinical tool for practitioners and although it is evidence-based, there is less emphasis on research and institutional applications of categories (Lingiardi & McWilliams, 2015). The manual consists of

three dimensions which patients are assessed against; the first is a classification of personality types, the second considers emotional functioning in various categories (e.g. self-regulation) and the third looks at specific symptoms (McWilliams, 2010). The PDM aims to capture the complexity of patient experience while also guiding treatment. The PDM is now in its second edition, published in 2017 (Lingiardi & McWilliams, 2017).

1.3.3. Psychological formulation.

Psychological formulation is increasing in popularity as an alternative to diagnosis in the assessment of potential mental health service users (Bruch & Bond, 1988; Johnstone & Dallos, 2006). Johnstone (2018) defines formulation as 'the process of co-constructing a hypothesis or 'best guess' about the origins of a person's difficulties in the context of their relationships, social circumstances, life events, and the sense that they have made of them' (p. 32). The replacement of diagnosis with formulation is supported by many authors including prominent clinical psychologists like Mary Boyle (2007), David Pilgrim (2016) and Lucy Johnstone (2018). The proposed benefits of formulation are that it is less pathologising of the individual, more collaborative and therefore empowering, less reductionist and provides a more comprehensive understanding than diagnosis. According to Johnstone (2018), a key difference between diagnosis and formulation is the conceptualisation of aetiology of distress. She argues that the explanation diagnosis provides to recipients is 'you have a medical illness with primarily biological causes' while formulation offers a more empathic view; 'your problems are an understandable emotional response to your life circumstances'(p. 39).

Research on formulation is as yet limited and results are mixed. Redhead, Johnstone and Nightingale (2014) found that psychological formulation was reported to enhance client

insight into their difficulties, facilitate a working relationship with the healthcare professional, alleviate strain and empower the individual. On the other hand, Chadwick, Williams and Mackenzie (2003) indicate that it can be experienced as overwhelming, worrying and distressing. Following a review of service user, clinician and carer perspective literature, Perkins et al. (2018) concluded that diagnosis may be more helpful to recipients if combined with elements of psychological formulation. However, Johnstone (2018) notes that combining a new approach with an unsatisfactory one can serve to bolster the latter rather than affecting real change. Despite its benefits, Boyle and Johnstone (2014) concede that as a replacement for diagnosis, psychological formulation may encounter similar pitfalls. Pilgrim (2016) acknowledges that, although potentially more helpful, formulation-based assessment is also 'profession-centred', a concern echoed by Duncan, Sparks and Timimi (2018).

1.3.4. Power Threat Meaning Framework.

Following the release of a position-statement from the BPS Division of Clinical Psychology, criticising psychiatric diagnosis and implying a disassociation from same (BPS, 2013), the division have published an alternative approach called the *Power Threat Meaning Framework* (Johnstone & Boyle, 2018). It is described by the authors as 'an over-arching structure for identifying patterns in emotional distress, unusual experiences, and troubling behaviour; as an alternative to psychiatric diagnosis and classification' (Johnstone & Boyle, 2018, p. 5). The framework is based on a fundamental belief that psychological distress is comprehensible within the context of an individual's past experience as an adaptive response to adversity. The framework proposes to replace the diagnostic interview with a formulation. This formulation will be based on the theory that the negative application of power poses a threat to the

individual particularly in emotional terms, meaning is then created around this which gives rise to the threat response or adaptation including unhelpful thoughts, defences or mental health presentations. This framework will in turn be used to identify patterns as an alternative to classifications such as the DSM and ICD. It claims to be more culturally-aware and applicable across cultures as it views individuals and meaning they ascribe in context. Additionally, it endeavours to be less pathologising by acknowledging unhelpful systemic processes rather than locating the problem within the individual.

Although this approach appears to address some of the most problematic aspects of psychiatric diagnosis, it is likely, as categorisation is by its nature reductionist, that this formulation structure will guide and restrict clinicians' view of individuals. Additionally, within this framework it is likely that some categories will be identified by service users, professionals, and the public as being more severe but hopefully given the emphasis on explanation and empathy within the framework, these categories will evoke less stigma than labels like schizophrenia and personality disorders.

1.3.5. Psychosocial codes

Similar to the developers of the Power Threat Meaning Framework, Kinderman, Read, Moncrieff, & Bentall (2013) assert that psychiatric diagnosis implies an 'underlying defect' in the individual by ignoring their circumstances and the context in which their mental health difficulties arose. Another alternative approach to the current psychiatric diagnosis paradigm, also based on linking symptoms or presenting problems with psychosocial factors, has been proposed by Prof Peter Kinderman and Dr Kate Allsopp (Allsopp & Kinderman, 2017; Kinderman & Allsopp, 2018). They suggest that psychosocial codes relating to a person's social, economic, and relational circumstances and experience, which already form part of the ICD and DSM

frameworks but are rarely included in service user notes, be recorded with symptoms or presenting problems on service user records. They argue that this practice offers an important advantage over clinical formulation alone, as it enables recording of psychosocial issues (potential causes of mental health difficulties) on a national scale which would contribute to research on the aetiology of psychological distress (Kinderman & Allsopp, 2018).

1.3.6. Phenomenological terminology.

It is important to include a widely-used alternative to formal psychiatric diagnosis, namely the use of ordinary terminology such as 'depression' or 'anxiety' rather than psychiatric/medical language e.g. 'major depressive disorder' or 'generalised anxiety disorder' when naming and discussing a mental health difficulty with clients/patients. This practice is rarely mentioned in research literature, however, two studies reviewed for this thesis found that some clinicians preferred to use more colloquial language rather than communicating a diagnosis of schizophrenia to their patients (Clafferty, McCabe, & Brown, 2001; Howe et al., 2014). A number of the alternatives to diagnosis listed above, psychological formulation, the Power Threat Meaning Framework, and the use of psychosocial codes, represent a departure from 'expert', technical, and medical language but in a more structured or formalised way than simply using ordinary terminology. Kinderman (2019) argues that abandoning psychiatric diagnosis does not mean denying the experience of psychological distress rather denying that it constitutes illness thereby attempting to break the association between the mind and ideas such as pathology which have their origins in biological medicine.

1.4. Researcher Position on Psychological Distress, Psychiatric Disorders, and Diagnosis

My philosophical position on mental health difficulties is that they are real and different from ordinary 'problems in living' (Szasz, 1961) in terms of severity. In 1961, in his iconic text, Thomas Szasz claimed that mental illness, as a concept, was a myth, and that all disturbance and distress of the mind represented 'problems in living' as a response to the suffering and anxiety inextricably associated with human life. However, for me this does not sufficiently capture the varying degree to which people experience these difficulties and perhaps risks minimising or even dismissing the struggles of those who encounter very significant distress and functional impairment. However, I also reject the idea that those who experience mental 'illness' are inherently distinct from those who do not. Therefore, I adhere to the notion of difference in terms of level of distress or functional impairment but do not believe that those experiencing mental health problems are qualitatively divergent from the 'psychologically well'. I see mental health and 'illness' on a continuum, in contrast with the medical paradigm of presence or absence of pathology. In essence, I believe that adverse psychosocial conditions impact neurological development which in turn causes the manifestation of the distress (National Scientific Council on the Developing Child, 2014) as opposed to the hypothesis that mental health difficulties, like physical diseases, are predominantly caused by biological abnormalities. Although I accept the idea that there may be genetic predisposition for mental health difficulties, it seems likely that like most genes, the expression of these depends on the individual's environment (Champagne & Curley, 2009; Taylor, 2010). Research on biomarkers for psychiatric difficulties and disorders is as yet inconclusive (Notter, Coughlin, Sawa, & Meyer, 2018; Singh & Rose, 2009), but studies suggests a strong relationship between adverse treatment and circumstances in

the early years of life and subsequent mental health difficulties, these effects remain when family history of mental illness is controlled for (Lewis, David, & Andreasson, 1992; Mortensen et al., 1999; Read, Bentall, & Fosse, 2009). Based on this evidence and from my clinical experience to date, I maintain that nurture is potentially more influential than nature in relation to an individual's mental health prospects. I take a critical realist position on psychiatric disorders in that I feel that they represent more than a 'by-product of professional activity' (Parker et al., 1995) but that the current diagnostic manuals and trends do not accurately capture the nature of psychological distress and dysfunction on the basis of poor inter-professional reliability (Freedman, 2013; Kitamura, Shima, Sakio, Kato, 1989) and general validity (Anckarsater, 2010; Middleton, 2008, Van Os, 2003). The categories do not appear to fit the people they are applied to, as evidenced by high levels of co-morbidity (Milton & Mullan, 2015; Moeke-Maxwell et al., 2008; Parker et al., 2014; Perkins et al., 2018; Ramon & Castillo, 2001; Ulfvebrand, Bigegard, Norring, Hogdahl, Hausswolff-Juulin, 2015) as well as frequent changes to diagnoses (Bromet et al., 2011; Laird et al., 2009; Moeke-Maxwell et al., 2008; Perkins et al., 2018; Thomas, Seebohm, Wallcraft, Kalthil, & Fernando, 2013)

I am agnostic on the issue of whether or not psychiatric diagnoses should be used in their current format in light of the points above and the fact that they are not necessary for treatment (Johnstone & Boyle, 2018) or predictive of treatment outcomes (Tamminga & Davis, 2007), however, some recipients find their diagnoses very containing and reassuring (Abbott, Bernard, & Forge, 2012; Cleradin, 2012; Delmas, Proudfoot, & Manicavasagar, 2011; Outram, Harris, Kelly, Bylund et al., 2014, Pitt, Kilbride, Welford, Nothard, & Morrison, 2009). Nevertheless, I am mindful of the expansion of diagnostic nosologies and increase in ascription of their labels. To me,

these suggest an unbridled quality to diagnostic practice where a more measured, research-based approach would be helpful.

My stance on mental health and psychiatric diagnosis is undoubtedly influenced by attitudes to these within my family and the wider cultural context in which I was raised i.e. rural Ireland in the 1990s and early 2000s. Diagnostic terms were rarely heard and there was a sense that it was insulting or unkind to use them when speaking about people. As a child, I would occasionally ask my father, a general practitioner, if friends of the family had mental health problems such as schizophrenia or depression. His response was typical of Irish vernacular discourse at the time, 'his nerves are at him', 'he's not himself at the moment', or 'she takes to the bed sometimes'. Once, when I asked why he didn't use the 'proper' terminology he explained that he thought they might find it hurtful to be referred to in that way. Subliminally, I learnt that to use psychiatric disorder terminology may be othering or offensive. To me, there is something more inclusive or normalising about the idea of having trouble with one's 'nerves' in comparison to having schizophrenia, although it is more likely that, in the context, the avoidance of disorder terminology reflected the fact that mental health was a taboo subject at the time rather than a tendency toward inclusivity. Nonetheless, there was a feeling that the intention behind this reluctance to label people was compassionate rather than marginalising. My personal experience of mental health diagnosis is mixed. I received a diagnosis of anxiety from a psychiatrist when I was 21, which at the time was quite containing in that it reassured me that I did not attract what I would have perceived to be a more severe label. However, due to the psychiatrist's particular style of consultation, I felt quite disempowered by the process. This was followed by another, more positive experience with a very compassionate and personable psychiatrist the following year. However, the label I received became incorporated into my view of

myself, and although at times the disorder term itself facilitated self-compassion, there is a psychological permanency to it that I don't like.

While studying psychological disorders as part of my psychology conversion course, I was sceptical about diagnostic classification and disorder criteria due to many stories I had heard about relatives and friends receiving multiple diagnoses, with some being given comorbid diagnoses. I struggled to take disorder categories seriously and found studying them somewhat meaningless and hollow. When I mentioned this to classmates it didn't seem to resonate with them and some playfully suggested that I was looking for ways to avoid learning the diagnostic criteria. While doing my doctorate, I was glad to discover a reflective and open-minded attitude to classification and diagnosis. For a period, I become increasingly opposed to diagnosis and in some ways enjoyed that feeling of taking a strong position on the topic. However, when I began clinical practice and started to review the literature on service-user perspectives on diagnosis, I was forced to acknowledge the potential benefits of diagnosis. Some of my clients had diagnoses and found them very helpful and comforting while others were frustrated that my role was not to ascribe diagnoses. There was a temptation, in my internal reflections, to intellectualise this and explain it away by undermining their awareness of what was helpful for them long-term, but I decided instead to take their perspective at face value.

I now find myself viewing diagnosis as a flawed solution to a very complex problem. Currently, in the absence of a officially sanctioned alternative, it fulfils a normal human need to know, to name and categorise experiences. That said, I still question the current system and believe that there is perhaps a better, more explanatory way of naming and understanding psychological problems than continuing with the medical paradigm of mental disorders which can lack reliability, validity, and

sometimes heart. Notwithstanding the above, the current study does not take a position on the merit (or otherwise) of psychiatric diagnosis. It comes from an attitude of genuine curiosity about the diagnosis recipient and service-user experience rather than an ‘interested’ stance of endeavouring to prove or disprove a particular hypothesis.

Chapter 2:

Literature Review

2.1. Introduction to Literature Review

The following literature review is based on research papers acquired by searching popular academic databases including Science Direct, PsychInfo, PsychArticles, and Web of Science. A broad range of search terms was used, these are included in Appendix A. These databases were also used to search relevant references from papers read. Initially, search terms were combined (e.g. impact of psychiatric diagnosis) and when relevant articles had been isolated single terms were searched (e.g psychiatric diagnosis). Overall, there was relatively little service user perspective research available, therefore a large number of search terms was used in an effort to maximise results. There were few relevant results yielded per search term which meant that all accessible and relevant (service user-perspective research relating to the impact of mental health diagnosis) papers were read.

This literature review endeavours to inform the reader on the current state of knowledge on the effect psychiatric diagnoses have on the lives of those who receive them. In line with this, the majority of studies below focus on the service user experience while some carer/family and clinician perspective studies have been included where diagnosis recipient literature was limited or where it seemed particularly relevant. I will also briefly discuss the relationship between counselling psychology and psychiatric diagnosis before concluding with a summary on the contributions of the current study to research and therapeutic practice.

2.2. Impact of Psychiatric Diagnosis on Service Users and Carers

2.2.1. Diagnosis and emotion.

In her capacity both as an author and diagnosis recipient, Callard (2014) encourages acknowledgement of the complex and varied emotional response psychiatric diagnoses can provoke in those who receive them. Consonant with this, a broad range of emotions was evident from service-user perspective literature.

2.2.1.1. Positive emotional impact of diagnosis.

Increased certainty or the end of ambiguity is mentioned in a number of studies. One of Laird et al.'s (2009) participants states; 'It puts a label to the symptoms- makes the uncertainty more certain' (p.5). Bamford et al. (2004)'s participants describe a sense of reassurance as they experienced diagnosis as verifying what they already suspected and bringing certainty. In Hayne (2003), the confirmation of a diagnosis and reduction in ambiguity was perceived as providing an increased sense that the problem could be managed. For some individuals, the receipt of a diagnosis is very powerful in validating their experience and represented an acknowledgment of their struggle (Abbott et al., 2012; Bilderbeck, Saunders, Price, & Goodwin, 2014; Delmas et al., 2011; Hayne, 2003; Vernooij Dassen et al., 2006).

Relief was a very common theme in the service-user literature reviewed (Abbott et al., 2012; Cleradin, 2012; Delmas et al., 2011; Outram, Harris, Kelly, Bylund et al., 2014, Pitt, Kilbride, Welford, Nothard, & Morrison, 2009). Parker et al. (2014) found that 65% of participants were relieved, 19% showed no reaction, 14% seemed shocked, 8% confused, 4% showed disbelief and 4% reacted in a humorous way. Reasons for this sense of relief include alleviation of previous concerns that symptoms indicated a 'more severe' disorder (Rose et al., 2012; Rose & Thornicroft, 2010), feeling less alone in the knowledge that others experienced similar distress (Moeke-Maxwell, Wells, & Mellsop,

2008), anticipating beneficial treatment (Laird et al., 2009; Moeke-Maxwell et al., 2008). However, Moeke-Maxwell et al. (2008) noted that this was short-lived when these expectations did not materialise, leaving participants with a sense of 'disappointment, disillusionment and anger'.

As above, diagnoses were at times well-received due to feelings of hope they inspired (Horn, Johnstone, & Brooke, 2007). This optimism was mainly due to an association between diagnosis and future mental wellbeing (Cleradin, 2012; Hayne, 2003; Parker et al., 2014). Parker et al. (2014) found that 87% of their participants diagnosed with bipolar disorder expected an improvement in their mood in the future.

2.2.1.2. Negative emotional impact of diagnosis.

Numerous studies mention the negative emotional impact that diagnoses can have on those who receive them (Abbot et al., 2012; Cleradin, 2012; Hasson-Ohanon, Kravetz, Roe, David, & Weiser, 2006; Hayne, 2003). Hayne (2003) reports that multiple participants likened the experience of diagnosis to 'a knife to the heart', and proposes that it threatens one's sense of belonging in a benevolent world.

Shock is a common response to a new psychiatric diagnosis. Recipients of diagnoses of schizophrenia and bipolar disorder recall reacting with disbelief (Cleradin, 2012; Outram, Harris, Kelly, Bylund et al., 2014) while recipients of a diagnosis of dementia reported feeling threatened by their diagnosis (Vernooij-Dassen, Derksen, Scheltens, & Moniz-Cook, 2006). Conversely, Parker et al.'s (2014) quantitative findings indicate that 79% of participants expected their diagnosis while 8% were very surprised by it. In a study of patients and family members, a bipolar disorder diagnosis was received more positively if it had been anticipated (Delmas et al., 2011).

Understandably diagnosis can be experienced as a stressful process. Crane, Chester, Goddard, Henry and Hill (2016) found that 56% of parents whose children

received an autism spectrum disorder diagnosis perceived the process to be ‘very stressful’ and 28% felt that it was ‘quite stressful’. Siklos and Kerns (2007) reported similar results from their qualitative study. In New Zealand, some participants with a range of disorders reported an initially negative response to their diagnosis, expressing confusion, shock, anger and feeling uncomfortable (Moeke-Maxwell et al., 2008). These feelings of confusion were echoed by Australian participants (Outram, Harris, Kelly, Bylund et al., 2014).

Diagnosis can be seen to provoke anxiety in recipients particularly about the future. According to Rose et al. (2012) diagnosis recipients are commonly concerned about the possibility of genetic transmission of mental health difficulties to their children. Participants with dementia fear developing increased disability (Vernooij-Dassen et al., 2006), while the idea of having a long-term illness was upsetting for participants with bipolar disorder, particularly as it was associated with permanency of treatment (Delmas et al., 2011).

For some, getting a mental health diagnosis can arouse feelings of loss and hopelessness. Some participants with a diagnosis of psychosis in a study by Pitt, Kilbride, Welford, Nothard, and Morrison (2009) reported that due to the lack of information given to them, it felt like a ‘prognosis of doom’ (p. 421). Participants in a study of ‘persistent and severe mentally ill clients’ identify a profound sense of loss following diagnosis. This is also a prominent theme in Cleradin’s (2012) research on bipolar diagnoses. Interestingly, individuals with dementia and their loved ones reported that the diagnosis allowed them to communicate feelings of loss and grief which they had struggled to do beforehand (Vernooij-Dassen et al., 2006). Bentall (2013) questions the usefulness and legitimacy of a diagnosis of schizophrenia in light of the associated connotations of hopelessness. Service-user studies also note the prominence of

hopelessness in participant narratives (Bassman, 2000; Cleradin, 2012; Horn et al., 2007; Keil, 1992; Thomas et al., 2013).

2.2.2. Diagnosis and identity.

Diagnosis is often seen as providing an explanation for psychological distress. It was described as explanatory or enhancing understanding of mental health difficulties in several studies (Bamford et al., 2004; Bilderbeck et al., 2014; Hayne, 2003; Laird et al. 2009; Pitt et al., 2009). Some participants in a study by Horn, Johnstone and Brooke (2007) concurred with this as they reported gaining a sense of 'knowing what was wrong' from receiving a name for their experiences, which they found helpful. In a conversation analysis of diagnostic interviews, Weiste et al. (2018) observed that eight out of twenty nine patients used their diagnosis as an explanation for their experiences.

Psychiatric diagnosis is generally thought to have a significant effect, whether beneficial or harmful, on the recipient's assessment and concept of him- or herself (Callard, 2014; Healy, 2004; Rose, 2004; Shackle, 1985; Terkelsen, 2009). Frequent references to identity and self-concept in service user perspective literature supports this theory. Horn et al. (2007) found that a psychiatric diagnosis can have a 'master status' whereby it eclipses other aspects of a person's identity, defining them.

A phenomenological study by Hayne (2003) found that some participants experienced a momentous shift in their sense of being, with one participant thinking, 'Oh my God, I have no idea who I am anymore' (p. 725). Another described an abrupt shift in his experience and said he felt completely different as a result of the diagnosis. Milton and Mullan (2015) found that a continued sense of self apart from the diagnosis was important to participants and they did not want to be defined by a disorder.

2.2.2.1. Negative impact on identity.

A systematic review of 78 studies showed clinicians and service users to be concerned about the impact of diagnosis on identity and emphasised the importance of follow up sessions to assess how the diagnosis is being processed by the individual and check for negative impact such as stigma (Perkins et al., 2018). Many recipients of diagnoses have reported experiencing the allocation of a mental disorder label as a judgement or pronouncement on their personality or self as a whole. In a UK study on personality disorder diagnoses, both service users and providers highlighted the broad nature of the diagnoses as problematic as it can feel like a judgement that recipients are inherently wrong in some way (Stalker, Ferguson, & Barclay, 2005). Similarly, Horn et al.'s (2007) participants saw their borderline personality disorder diagnosis as meaning their whole beings and personalities were worthless. This is in line with results of a study on 'severe and enduring mental illness' by Hayne (2003), suggesting the holistic interpretation of diagnoses by recipients and experience of these as absolute declarations on their 'selves'.

Research suggests that the internalisation of these perceived criticisms can have a catastrophic effect on the individual's sense of self, particularly in the case of more 'severe' diagnoses. Milton and Mullan's (2015) study on people identifying with 'serious mental illness' found that self-stigmatization following diagnosis eroded participants' sense of self-worth. Horn et al.'s (2007) participants with a diagnosis of borderline personality disorder experienced it as a rejection and subsequently internalised this and incorporated it into an already well-established schema of feeling inherently 'wrong' in some way. This is consistent with Castillo's (2000) finding that the stigma associated with a borderline personality disorder diagnosis risks 'reinforcing a damaged sense of self' (p. 58). Conversely, rejection of a diagnosis may protect

against this. A study by Bassman (2010) suggests that the diagnosis recipient's attitude to the diagnosis is a mediating factor in how their identity is affected, with acceptance of a schizophrenia diagnosis being associated with reduced self-esteem, hopelessness and despair.

Some diagnoses, particularly those viewed in society as 'more severe' can cause recipients to worry about their identity and question themselves. Howe, Tickle and Brown (2014) reported one participant's concerns that she might be dangerous following her diagnosis of schizophrenia. Similarly, in Horn et al.'s (2007) study on borderline personality disorder, one participant recalled wondering if she should have been in prison based on online research on the disorder, despite nothing in her experience or behaviour suggesting this.

Many authors point to the long-term identity issues experienced by those who receive diagnoses as well as its impact on aspirations and quality of life (Knight, Wykes, & Hayward, 2003; Sayce, 2000; Warner, 1994, 2000). One participant in Hayne's (2003) study described feeling inferior to the person she was, pre-diagnosis, while one of Horn et al.'s (2007) participants interpreted her diagnosis of borderline personality disorder as meaning she was a troublemaker as it did not seem like a legitimate illness to her.

Cleradin (2012) reports numerous participants struggling to establish a stable sense of self subsequent to a diagnosis of bipolar disorder and refers to a bipolar disorder II diagnosis causing, 'scarring of the individual's innate sense of self' (p.173), as well as an enduring experience of trauma and attack on their self-concept. Horn et al.'s (2007) findings suggest that internalising negative aspects of the diagnosis affects treatment and recovery as participants described withdrawing from services following the experience of diagnosis as rejecting.

2.2.2.2. Positive impact on identity.

Although less prominent in the literature, diagnosis can be found to positively impact identity. From their findings, Watson et al. (2007) deduce that if individuals manage to escape or withstand stigma, they can gain a sense of support from being part of a wider group thus strengthening their individual sense of identity. Hayne's (2003) participants felt that in the context of an empowering and informative communication of diagnosis, it could lead to an improved sense of self due to 'knowing what's wrong' (p. 727). They also described the transmission of knowledge, represented by the diagnosis, as affording a new interpretation of the self which facilitated changes to their lives.

Haynes' (2003) participants with 'severe and enduring' mental health diagnoses presented a conflicted sense of identity, on one hand they felt their diagnosis facilitated a better understanding of self while simultaneously threatening the self-concept they had established prior to diagnosis. This theme of incongruence and confusion was prominent in participant's descriptions of the impact of a diagnosis on their identities as it was seen to imply both positive and negative characteristics.

Research indicates that a clinical context that empowers consumers and helps them to develop a positive self-concept is essential to 'recovery' (Mancini, Hardiman & Lawson, 2005; Tew et al., 2012). Shea (2010) found that integrating the 'schizophrenic' identity into a new view of the self can be part of recovery, suggesting that internalisation of the diagnosis may have treatment benefits in some cases. Unsurprisingly, research suggests that a positive self-identity is integral to improving wellbeing in mental health service users (Mancini et al., 2005; Tew et al., 2012).

2.2.3. Diagnosis and power.

Milton and Mullan (2015) found that professionals promoting empowerment and a sense of agency was crucial to participants feeling hopeful that they could

contribute to society and have meaningful lives as well as having a psychiatric diagnosis.

2.2.3.1. Diagnosis and disempowerment.

Some research on psychiatric diagnosis suggests that the public stigma related to diagnosis can cause a substantial sense of powerlessness (Pitt et al., 2009) due to connotations of chronic fragility (Hayne, 2003). Howe, Tickle, and Brown's (2014) results indicate that service users found that the presentation of a biological aetiology concept of schizophrenia by clinicians decreased optimism regarding recovery and promoted a self-positioning as a passive consumer of care. Similarly, Knight, Wykes, & Hayward (2003) found that some diagnosis recipients adapt to their diagnosis by thinking and behaving in a disempowered way that is consonant with their highly stigmatised schizophrenia label.

Some studies have shown that recipients of diagnosis can experience a pronounced power differential between themselves and healthcare professionals. Two studies (one on schizophrenia and the other on borderline personality disorder) report participants who felt that querying or rejecting the diagnosis would be interpreted as being symptomatic of the diagnosis given and therefore would support it (Horn et al., 2007; Thomas et al., 2013). In line with this, Hayne (2003) reports that diagnosis can create a power discrepancy between the holder and professionals. Horn et al. (2007) also found that in general, participants felt that diagnosers were more knowledgeable than them, indicating a possible reason for the power differential suggested by Hayne (2003).

Although it may seem natural for others to be more protective of an individual who has been identified as having an illness or disorder, as it is often presented in mental health contexts, research has found that this reaction can be experienced as

disempowering and unhelpful. Howe et al. (2014) reported that people with a diagnosis of schizophrenia, in addition to experiencing 'over-concern', found that others seemed to imply that they lacked intelligence and competence.

In Hamilton et al.'s (2014) study, six participants of 23 described others being overprotective of them. In spite of this being well-intended, it was experienced as discriminatory. Depending on the individual's tendency to internalise, this kind of treatment may be quite disempowering, with some people potentially interpreting it as meaning they require such levels protection and care.

In a similar vein, participants in some studies have described a sense of dismissiveness associated with their diagnosis. Bilderbeck (2014) reported 'several' participants with bipolar disorder and borderline personality disorder diagnoses feeling the diagnosis itself was dismissive. Diagnosis is also linked to recipients being perceived as less credible by others in relationships and social situations. Participants in Hamilton et al. (2014) identified their diagnosis as a reason for others, particularly family members, to dismiss them or question their claims and experiences. One participant with a schizophrenia diagnosis described being disbelieved by her sister who used the participant's diagnosis to support her doubt.

2.2.3.2. Diagnosis and agency.

In Laird et al.'s (2009) study 14 family members and carers reported diagnosis leading to the recipient 'taking greater responsibility for their wellbeing' while six participants reported the opposite effect from service users who did not accept their diagnosis. Horn et al. (2007) cite three out of five participants with a diagnosis of borderline personality disorder finding their diagnosis helpful in terms of giving them more control and a route to follow toward greater wellbeing. In a study on dementia, Vernooij-Dassen et al.'s (2006) findings indicate that, three months following their

diagnosis, some participants wanted to make the most of their autonomy while others experienced the loss of it which was very difficult.

For some, a diagnosis can relieve a sense of guilt and responsibility for past actions and even release individuals from self-loathing due to their difficult internal and emotional experiences (Bilderbeck et al., 2014). In Pitt et al.'s (2009) study diagnosis facilitated participants' externalisation of problems which aided understanding of their experience. A number of participants in Moeke-Maxwell et al.'s (2008) study described being able to 'hand the problem over to the doctor'. However, despite a sense of absolution from blame and guilt having a positive emotional effect, Weiste et al.'s (2018) findings suggest that attributing behaviour to a diagnosis risks eroding an individual's sense of agency.

2.2.3.3. Diagnosis and access to information.

Many studies have found that participants experience their diagnosis as useful in searching for information on their condition and carrying out independent research. Participants with bipolar disorder found that accessing information helped them to accept the diagnosis (Delmas et al., 2011). Caregivers of individuals with schizophrenia diagnoses found the label helpful in allowing them to research their loved one's condition (Outram et al., 2014), this was echoed by family members and carers in Laird et al.'s (2009) study. Conversely, following interviews with 12 service users and ten service providers, Stalker et al. (2005) concluded that a personality disorder diagnosis did not bring this sense of power triggered by access to information due to the lack of certainty and consensus on these disorders.

2.2.4. Diagnosis and social life.

2.2.4.1. Stigma.

A review of the research literature shows stigma to be the most frequently cited negative consequence of mental health diagnosis and one of the principal arguments against the practice of diagnosis (Laird et al., 2009; Link & Phelan, 2001; Manderscheid et al., 2010). This raises questions about the beliefs involved in stigmatisation.

Hayward and Bright's (1997) analysis of mental health stereotypes showed four subcategories: perceptions of dangerousness, unpredictability and inability to adhere to social norms, recipient responsibility for illness, and chronicity and poor prognosis. Research suggests that the perception of people with mental health problems as being dangerous is common and a prominent root of marginalisation or social distance (Angermeyer & Matschinger, 1997, 2005; Link, Phelan, Bresnahan, Strueve, & Pescosolido, 1999; Martin, Pescosolido, & Tuch, 2000; Nunnally, 1981; Thornicroft, 2006). Thornicroft (2006) cites the link between mental illness and violence as a significant disadvantage of having a psychiatric diagnosis. In Laird et al.'s (2009) qualitative study on family and carers of psychiatric service users, participants reported others' perceptions of their relatives as dangerous because of their diagnosis.

Stigmatisation of those with mental health difficulties is well-documented and reported. Falk (2001) termed mental illness the 'ultimate stigma'. However, in recent years an increasing body of evidence has emerged which suggests that mental health diagnoses, independent of the experience of psychological distress, result in discrimination toward those who receive them. Participants in two studies reported anxiety related to anticipation of diagnosis-related stigma (Bilderbeck et al., 2014; Vernooij-Dassen et al., 2006). Several studies reported participants experiencing discriminatory behaviour which they attributed to their diagnosis (Hamilton et al., 2014;

Howe et al., 2014; Laird et al., 2009; Link, 1987; Moeke-Maxwell et al., 2008; Thomas et al., 2013; Uhlmann et al., 2014). Laird et al. (2009) found that participants who perceived their diagnosis to be unhelpful felt that the stigma associated with it was the worst consequence. Thornicroft, Brohan, Rose, Sartorius, and Leese (2009) capture the problem well; '…there is no known country, society or culture in which people with a diagnosis are considered to have the same value and to be as acceptable as people who do not have mental illness' (p. 143).

2.2.4.2. Impact of stigma.

Social distance is identified by Hamilton et al. (2014) as a key dimension of discrimination. They report that 11 participants gave 16 examples of behaviour which was considered to be social distancing. However, this was linked to the disclosure of psychological difficulties rather than the diagnosis itself. Marginalisation of people who experience mental health difficulties is well-documented (Arens, 1993; Bahlmann et al., 2013; Wheat et al., 2010) but as yet there is a lack of research on social distance due to mental health diagnosis. However, all of Pitt et al.'s (2009) participants identified their diagnosis as possibly causing social exclusion with some adding that they were dubious about telling new acquaintances their diagnosis due to fear of negative reactions.

Unfortunately, because mental health stigma levels are high in the general population, loved ones of service users too hold negative perceptions of psychological illness. Large-scale surveys have found that over half of participants experienced discrimination from family (Henderson, Corker, Lewis-Holmes et al., 2012) and friends (Hamilton et al., 2014) because of their diagnoses.

Link et al.'s (1999) findings suggest that stigma associated with mental health difficulties may impede treatment-seeking thus having a detrimental impact on mental wellbeing. Gold et al. (2016) and Cheung, Mak, Tsang, and Lau (2018) also cite stigma

as a serious barrier to people pursuing mental health treatment. This is in keeping with a significant body of service-user perspective research on mental health problems (Cheung, Mak, Tsang, & Lau, 2018; Moeke-Maxwell et al., 2008). More specifically, stigma related to diagnosis has been seen to impede treatment-seeking behaviours. Howe et al. (2014) found that some participants did not seek help due to fear of being diagnosed with schizophrenia which they saw as a highly stigmatised label. Similarly, Uhlmann et al. (2014) indicate that a diagnosis of psychosis caused treatment delays.

Some diagnosis recipients internalise common perceptions of mental illness resulting in a negative self-image/attitude, this is known as self-stigma which is a subtype of stigma (Corrigan & Rao, 2012; Pescosolido & Martin, 2015). Link et al. (1989) found that this internalisation led to issues with self-esteem and avoidance of others. Magliano et al. (2008) surveyed 241 individuals with a diagnosis of schizophrenia and found that the majority of these shared the public's negative and stigmatizing views on the disorder. According to research by Smart and Wegner (1999), over-identification with a diagnosis can lead recipients to be defined by it, rather than incorporating it into an existing self-concept, leading to decreased self-worth (Smart & Wegner, 1999). In the same vein, participants commonly experience a diagnosis as personally stigmatising (Horn et al., 2007; Romme, Escher, Dillon, Corstens, & Morris, 2009; Sayce, 2000). Milton and Mullan's participants (2015) suggested that it may be helpful to discuss self-stigma at diagnostic interviews to mitigate the effect of labels on individuals.

2.2.4.3. Social benefits of diagnosis.

Although diagnosis is often associated with stigma, it can also be socially beneficial. Service-user and family perspective research suggests that in some cases, a diagnosis can enhance relationships within families, with relatives reviewing their role

in the recipient's life (Vernooij-Dassen et al., 2006), their perspective on the person's capacity for control over their behaviour (Outram, Harris, Kelly, & Bylund et al. 2014), and becoming more understanding (Horn et al., 2007; Laird et al., 2009; Pitt et al., 2009). In addition, diagnosis can broaden a recipient's social circle by introducing them to others with the same or similar diagnoses. Some research participants have noted peer support as an important and helpful result of diagnosis (Howe et al., 2014; Milton & Mullan, 2015; Pitt et al., 2009).

2.2.5. Diagnosis and treatment.

2.2.5.1. Positive impact of diagnosis on treatment.

One of the principal academic arguments in favour of diagnosis is the facilitation of access to services or the triggering of a treatment response. Access to treatment is frequently cited as an advantage of diagnosis by participants in service-user perspective research.

In a review of 78 research papers on mental health diagnosis, Perkins et al. (2018) found that service users deemed a diagnosis to be helpful when it had a functional value in terms of access to suitable treatment and aiding recovery. Conversely, in the absence of this it was viewed as destructive, potentially leading to negative feelings about the future and towards services. Many studies reported participants finding their diagnosis helpful in getting treatment (Abbott et al., 2012; Bamford, 2004; Cleradin, 2012; Hayne, 2003; Howe et al, 2014; Laird et al., 2009, Pitt et al., 2009). The diagnosis seems to serve as a declaration of illness which is necessary to access help (Hayne, 2003; Weiste et al., 2018). Most participants in Howe et al.'s (2014) IPA study on schizophrenia described their diagnosis as facilitating helpful treatment. One of the families interviewed in Outram et al.'s (2014) study found that an absence of a correct diagnosis led to insufficient treatment giving rise to the individual

being incarcerated and hospitalised. Hayne (2003) indicates the profound impact of diagnosis leading to treatment; 'Participants spoke to healing gained from a diagnosis which made illness evident and possible, thus, reinstating them to life' (p. 726).

2.2.5.2. Limited impact of diagnosis on treatment.

Diagnosis can be important in securing support for children with autism spectrum disorders and their families (Mansell & Morris, 2004; Midence & O'Neill, 1999). However, a review of the literature suggests very limited provision of assistance, a finding reinforced by UK participants in Crane et al.'s (2016) survey of 1047 parents, a third of whom reported no offers of support during or after the process of diagnosing the disorder. Similarly, Moeke-Maxwell et al. (2008) found that in a sample of Maori and non-Maori service users with a range of mental health diagnoses, the label was not viewed as being significant or helpful in terms of recovery.

Howe et al. (2014) reported that all participants with schizophrenia were incorrectly diagnosed with depression because of their active avoidance of what they perceived to be a more stigmatizing diagnosis. This resulted in, 'unnecessary distress and prevention of early intervention' (p. 155), indicating that diagnosis-specific stigma has the potential to have serious implications for the mental wellbeing of those in distress. On the other hand, a personality disorder diagnosis has been perceived by recipients as preventing them from accessing desired services (Stalker et al., 2005). Similarly, some individuals perceive a diagnosis of BPD as precipitating a withdrawal of support from services (Horn et al., 2007).

A number of papers suggest that individuals with personality disorder diagnoses experience discrimination within services due to this label. Research indicates that mental health staff consider those with borderline personality disorder (BPD) diagnoses to be mostly agentic in their destructive actions and are therefore less empathic toward

them (Gallop, at al., 1989; Lewis & Appleby, 1988; Markham & Trower, 2003). Ramon and Castillo (2001) reported a similar finding, noting that personality disorder diagnoses cause healthcare professionals to display unhelpful attitudes toward recipients, with 72% of participants feeling they were treated badly because of their diagnosis. Castillo (2000) found that the label causes such distress to recipients that they behave in a manner that induces a negative reaction from services thus inhibiting care. Stalker et al.'s (2005) participants noted a lack of therapist optimism in dealings with professionals which they attributed to their diagnosis.

2.2.6. Diagnosis and finance.

Payment or reimbursement for healthcare by insurance companies is often conditional on service users having a psychiatric diagnosis, particularly in the US (Callard, 2014; Maddux, 2016; Weiste et al., 2018). It can also be necessary when claiming social benefits and to justify state-funded, particularly long-term, care (Campbell, 2007; Moncrieff, 2010; Rose et al., 2012).

However, diagnosis can also have negative financial consequences due to the associated stigma (Rose & Thornicroft, 2010). Research by Hamilton et al. (2014) suggests that people with mental health diagnoses pay higher insurance premiums than customers without documented mental health concerns.

2.2.7. Diagnosis and employment.

Diagnosis is sometimes found to be helpful in relation to work and facilitating changes or allowances in the workplace (Weiste et al., 2018). Callard (2014) refers to her diagnoses being used by medical professionals and occupational health to support claims that she needed to be granted sick leave from her job.

However, more literature suggests that having a psychiatric diagnosis prevents holders from securing employment, keeping their jobs and earning the same as those

without diagnoses (Alexander & Link, 2003; Link, 1982; Link & Phelan, 2001; Overton & Medina, 2008: Thomas et al., 2013). In spite of the Equality Act 2010 (Legislation.gov.uk, 2010), the Organisation for Economic Cooperation and Development (2014) found that the employment rate for people with mental disorder diagnoses in the UK is 50% lower than those without, with profound effect on people with severe mental illness (Caron, Mercier, Diaz, & Martin, 2005). Although it could be argued that the effects of mental illness itself may mean that some people with diagnoses are not well enough to work, individuals who are coping well with symptoms also report difficulties in securing and maintaining employment (Corrigan, 2004; Rusch, Angermeyer, & Corrigan, 2005). Findings of a large-scale German study (N=748) by Mendel, Kissling, Reichhart, Buhner, and Hamann (2013) suggest that managers have a more negative attitude to employees with mental health difficulties compared to those with physical health issues.

As is the case with many negative consequences of diagnosis, the relationship between having a diagnosis and experiencing employment difficulties seems to be due to the presence of stigma (Hayward & Bright, 1997; Overton & Medina, 2008). Low employment rates relative to those without diagnoses are thought to be because of discrimination, either experienced or anticipated by potential job applicants (Lasalvia et al, 2013; Rusch et al., 2005). A number of studies have found that people with diagnoses experienced stigma in the workplace (Brouwers et al., 2016; Farrelly et al., 2014; Lasalvia et al., 2013; McApline & Warner, 2002). Anticipated discrimination is also seen as a major obstacle for people with mental health diagnoses as it can prevent individuals from looking for work (Farrelly et al., 2014; Hamilton et al., 2014; Rose et al., 2012; Yoshimura et al., 2018). Research suggests that individuals with psychiatric diagnoses are reluctant to reveal them in their place of work due to potential

discrimination (Ahola et al., 2012; Brohan et al., 2012; Czabala et al., 2011; Little et al., 2011; Social Exclusion Unit, 2004; The Schizophrenia Commission, 2012; Pitt et al., 2009; Wheat, Brohan, Henderson, & Thornicroft, 2010).

2.2.8. Diagnosis and education.

Research on the impact of diagnosis on education is very sparse, however, studies to date suggest that it can have a very significant effect. In a survey of over a thousand parents of children diagnosed with an autism spectrum disorder, educational provision was given as the most significant benefit of the diagnosis (Crane et al., 2016). Conversely, psychiatric diagnosis can impede access to education. Yoshimura et al. (2018) found that participants with a diagnosis of depression were more likely to avoid education and training than those with schizophrenia or schizoaffective disorder diagnoses, while personality disorder diagnoses were most associated with education and employment avoidance. The avoidance mentioned here is reported by participants as being due to anticipated or feared discrimination. The relationship is therefore moderated by anticipated stigma. Interestingly, Quinn, Kahng, and Crocker (2004) found that the disclosure of a mental health diagnosis had an impact on student performance on a reasoning test. Students who concealed their diagnosis got better results than those who revealed it. The researchers propose that this is the result of internalised stigma.

2.3. Factors Affecting the Impact of Psychiatric Diagnosis

2.3.1. Diagnosis and communication.

Communication of and about psychiatric diagnosis appears to greatly impact the recipient's experience of the diagnostic process and the diagnosis itself (Milton & Mullan, 2015; Crane et al., 2016). Laird et al. (2009) found that in the case of Maori and

non-Maori carers, effective communication increased understanding of their family member's situation meaning diagnosis was viewed as helpful.

2.3.1.1. Service user awareness of diagnosis.

Research suggests that knowledge of a diagnosis varies across people registered as having one. Magliano et al. (2008) found that only 30% of 241 Italian participants with a diagnosis of schizophrenia had had their diagnosis communicated to them by a psychiatrist despite 72% expressing a belief that they should be told about their diagnosis by mental health professionals. Similar findings were reported in a study on schizophrenia (Read et al., 2006). However, in a survey of 27 countries, Thornicroft et al. (2009) reported that 83% of participants with schizophrenia (n=728) knew their diagnosis and the majority of service users in a qualitative study in Scotland who were diagnosed with personality disorders (n=12) knew their diagnosis (Stalker et al., 2005). A number of studies suggest that of those who are aware of their diagnosis, many find out indirectly rather than being told by a healthcare professional (Callard, 2014; Castillo, Allen, & Coxhead, 2001; Magliano et al., 2008; Outram et al., 2014; Pitt et al., 2009; Stalker et al., 2005; Thomas et al., 2013) which was experienced as distressing or unhelpful by most.

2.3.1.2. *Service user attitude to diagnosis communication.*

Studies on mental health diagnosis suggest that having a specific disorder name communicated was valued by service users and family carers (Cleary, Hunt, & Horsfall, 2010; Howlin & Moore, 1997; Jha, Tabet, & Orrell, 2001; Magliano et al., 2008; Milton & Mullan, 2015; Outram, Harris, Kelly, Bylund et al., 2014; Shergil, Barker, & Greenberg, 1998), regardless of negative associations with the diagnosis (Fisher, 2000; Magliano et al., 2008; Schneider et al., 2004). The practice of non-disclosure of diagnoses has been identified as unhelpful by recipients (Bamford et al, 2004;

Bilderbeck et al., 2014). In countries such as Japan, where the term ‘schizophrenia’ has been replaced with a new label, research reports indicate increased levels of diagnosis communication to patients (Goto, 2003; Kim & Berrios, 2001; Mino, Yasada, Tsuda, & Shimodera, 2001).

2.3.1.3. Unsatisfactory communication.

Sometimes, receiving a diagnosis can be upsetting for individuals due to unsatisfactory communication. Outram, Harris, Kelly, Bylund et al. (2014) reported caregivers finding the communication of their relatives’ diagnosis traumatic and chaotic. Some parents of children who received a diagnosis of an autism spectrum disorder were unhappy with communication during the diagnostic process (Abbott et al., 2012; Brogan & Knussen, 2003; Hackett, Shaikh, & Theodosiou, 2009; Mansell & Morris, 2004; Osborne & Reed, 2008). In addition, too much information was experienced as unhelpful (Abbott, Bernard, & Forge, 2012) as were vague explanations of the diagnosis (Howe et al., 2014; Stalker et al., 2005). Similar frustration was expressed by those who felt there was a lack of meaningful communication or insufficient information given by professionals (Horn et al., 2007; Laird et al., 2009; Moeke-Maxwell et al., 2008; 2009; Outram, Harris, Kelly, Bylund et al., 2014; Pitt et al., 2009). Participants in two studies suggested that it would be helpful to be given information to take home (Abbott et al., 2012; Milton & Mullan, 2015). Pitt et al.’s (2009) participants reported that when there was a lack of information with their diagnosis, there was a greater likelihood of feeling adversely labelled.

2.3.1.4. Clinician reluctance to diagnose.

Some mental health professionals have expressed apprehension in giving a diagnosis (Clafferty, McCabe, & Brown, 2001; Iliffe, Manthorpe, & Eden, 2003; Mitchell, 2007; Outram, Harris, Kelly, Cohen, et al., 2014). In Outram, Harris, Kelly,

Cohen et al. (2014) reasons given for this were concerns about stigma, anxiety around potentially giving an incorrect diagnosis and not wanting to cause distress to patients. Research suggests that professionals sometimes use synonyms for schizophrenia (Howe et al., 2014) and other disorders (Clafferty, McCabe, & Brown, 2001) rather than communicating diagnostic terms.

2.3.1.5. Hope and support.

Giving hope and support to diagnosis recipients and their families seems to improve what can be a stressful and upsetting situation. Parents in Abbott et al.'s (2012) study on autism spectrum disorder diagnoses emphasised the importance of optimism. Likewise, Milton and Mullan's (2015) participants with 'serious mental health diagnoses' identified hopeless communications as paralysing and potentially increasing risk. Horn et al. (2007) found that all participants experienced a very negative, pessimistic message from clinicians which they found damaging. In the same vein, supportive professionals were perceived as very helpful by parents in Abbott et al. (2012) and encouragingly, almost all parents found clinicians supportive. Service users in Milton and Mullan's study (2015) emphasised the importance of support from staff in mitigating unhelpful effects of diagnosis.

2.3.1.6. Collaboration.

Participants in many studies have emphasised the importance of a collaborative diagnostic encounter in terms of processing the label and engaging with treatment (Bilderbeck et al., 2014; Milton & Mullan, 2015; Moeke-Maxwell et al., 2008; Rose, 2001). However, there is a significant proportion who do not have such an experience (Milton & Mullan, 2015; Weiste et al., 2018).

2.3.2. Diagnosis and Time.

2.3.2.1. Time since diagnosis.

There is notable variability in the perceived influence of time on the experience of having a mental health diagnosis. Vernooij-Dassen et al. (2006) interviewed individuals with a diagnosis of dementia and their family members at two and twelve weeks post-diagnosis and reported slight differences in emotional impact and practical developments at 12 weeks. Delmas et al. (2011) reported that some participants found time to be crucial in accepting a bipolar disorder diagnosis while Bilderbeck et al. (2014) reported no effect of time elapsed on participant views. Other studies report an increasingly negative attitude to diagnosis over time but this appears to be due to expectations not being realised rather than time per se (Cleradin, 2012; Moeke-Maxwell et al., 2008).

2.3.2.2. Delays in receiving a diagnosis.

Some studies report participants experiencing substantial delays in receiving a diagnosis (Highet, McNair, Thompson, Davenport, & Hickie, 2004; Parker et al., 2014; Outram, Harris, Kelly, Bylund et al., 2014; Outram, Harris, Kelly, Cohen, et al., 2014). Research overwhelmingly indicates that delays in receiving a diagnosis were experienced as unhelpful (Abbott et al., 2012; Cleradin, 2012; Crane et al., 2016; Howlin & Moore, 1997; Moeke-Maxwell et al., 2008; Parker et al., 2014). However, it is not clear from these studies what constituted a delay and or if delays resulted from difficulty diagnosing or delay in being assessed by mental health services.

2.3.3. Diagnosis fit.

Diagnoses are reported to be helpful by recipients when they map on to their experience of psychological difficulties and they seem to be a good fit (Perkins et al., 2018; Rose & Thornicroft, 2010). However, when the diagnosis does not seem to

describe the recipient's problems or fully capture their distress they were poorly received and seen as unhelpful (Bilderbeck et al., 2014; Highet et al., 2009; Horn et al., 2007; Laird et al., 2009).

2.3.4. Multiple diagnoses.

Four studies reported that all or most of their participants received more than one diagnosis in their lifetime (Milton & Mullan, 2015; Moeke-Maxwell et al., 2008; Parker et al., 2014; Ramon & Castillo, 2001).

Many participants reported that changes in diagnoses often occurred when a new psychiatrist was allocated (Laird et al., 2009; Moeke-Maxwell et al., 2008; Thomas et al., 2013). 10% of participants in Thomas et al. (2013) expressed unease and suspicion about the frequency with which their diagnosis changed. These findings may indicate issues with continuity of care and diagnosis reliability. Accounts of perceived usefulness of changes to diagnoses are mixed, they were seen as helpful if they led to appropriate care or were a better fit than previous diagnoses (Milton & Mullan, 2015) but some participants needed more comprehensive explanations for the change (Milton & Mullan, 2015) and others found them disruptive and confusing (Moeke-Maxwell et al., 2008). Milton and Mullan (2015) conclude that it may be helpful to prepare individuals for the possibility that their diagnosis may evolve over time and explain the reasons for this development when ascribing a first diagnosis.

2.3.5. Type of diagnosis.

Research indicates that the specific disorder label individuals receive may predict how diagnosis impacts their lives (Ellison, Mason, & Scior, 2013; Yang, Anglin, Wonpat-Borja, Opler, Greenspoon, & Corcoran, 2013).

Personality disorder diagnoses have, in some research, been identified as having more of a negative impact than others. Perkins et al. (2018) found that poor

communication and non-disclosure of diagnosis to service users was most commonly associated with personality disorder diagnoses and psychotic diagnoses. They were also found to be more likely to adversely affect identity and optimism than other diagnoses. Personality disorder diagnoses were most associated with withdrawal of care and deemed to be least helpful in practical terms. Furthermore, they were most predictive of discrimination from mental health services while other diagnoses were more likely to provoke social stigma. In contrast, Bilderbeck et al. (2014) found no significant difference between borderline personality disorder and bipolar disorder in terms of experience of denigration and stigma. However, the sample used was quite small for quantitative research (n=28) which suggests that this finding may not be generalisable.

Like personality disorder diagnoses, a diagnosis of schizophrenia is also reported to have a more detrimental effect on recipients than other labels. Individuals with this diagnosis report more frequent discrimination than those with depression and bipolar disorder (Angermeyer, Beck, Dietrich, & Holzinger, 2004; Crisp, 2004; Ellison, Mason, & Scior, 2013). In Howe et al.'s (2014) study, some participants stated that they did not disclose their diagnosis to others due to the 'unique stigma' associated with it. Additionally, Perkins et al. (2018) found that insufficient support from family and carers was associated with a psychosis diagnosis over all others. Mental health professionals report reluctance to ascribe a diagnosis of schizophrenia. According to Lakoff (2006), Argentinian psychiatrists initially give a diagnosis of bipolar disorder to those with psychotic symptoms to protect them from the stigma associated with schizophrenia. Similarly, professionals in Outram, Harris, Kelly, Cohen et al.'s (2014) study were in favour of telling patients their diagnosis of schizophrenia in theory but many avoided doing so in practice due to the negative associations with this label. However, some

studies have reported no significant differences between schizophrenia and other diagnoses (Farrelly et al., 2014; Yoshimura et al., 2018).

2.4. Psychiatric Diagnosis and Counselling Psychology

Counselling psychology as a profession can be thought of as coming from a position of inherent conflict as it is rooted in two opposing epistemologies (Williams & Irving, 1996), positivism by way of affiliation with psychology and the scientist-practitioner model and phenomenology in the form of humanism (Larsson, Brooks, & Loewenthal, 2012). Counselling psychologists are more frequently employed in statutory and NHS settings now compared to when the profession was formed in the 1990s (Davies, Halewood, Johnstone, & Waite, 2017; Douglas, 2010). Indeed, some counselling psychologists may find that service-users expect them to give a diagnosis and some may be required to diagnose as part of their roles (Davies et al., 2017). This relationship with statutory services has prompted changes within the discipline and presented ideological conflicts and dilemmas for practitioners. According to Golsworthy (2004) the incorporation of counselling psychology into the NHS has influenced practitioner training, with inclusion of the medical model framework in programmes.

It is argued that adoption of the medical model and associated nosologies may be incompatible with the humanistic values that the profession is based on (Davies et al., 2017; Eriksen & Kress, 2006; Strawbridge & Woolfe, 2010). Indeed, according to Craven and Coyle (2007), many counselling psychologists report feeling ambivalent about diagnosis. Some propose that acceptance of this model jeopardises the unique contributions that counselling psychology offers (Lane & Corrie, 2006). Turner-Young (2003) likens counselling psychology's involvement in a medically-dominated system to succumbing to peer pressure as opposed to a braver and more solitary challenge of it.

Furthermore, Golsworthy (2004) asserts that counselling psychologists have a duty to oppose medical nosologies regardless of the professional repercussions.

However, other authors have highlighted the difficult position that counselling psychologists are now faced with as they are more frequently employed by the NHS. According to Corrie and Callahan (2000) in order to progress within the NHS, counselling psychology must inhabit the role of scientist-practitioner and support evidence-based practice. Sequeira and van Scoyoc (2002) argue that opposition of classifications by counselling psychologists would be fruitless and unwise as it compromises their integration into the healthcare system. Larsson, Brooks, and Loewenthal (2012) propose that the complex origins of and epistemological contradictions inherent in counselling psychology may be advantageous if practitioners can harness them and hold multiple perspectives and understandings. Chwalisz (2003) suggests, hopefully, that the unique stance of counselling psychologists may allow them to affect change in the medically dominated healthcare system from the inside rather than having their values eclipsed by it.

2.5. Rationale for the Current Study

2.5.1. Contribution to research.

Although psychiatric diagnosis has been debated for decades by academics and remains topical among professionals, there is a relative paucity of research investigating its effect on recipients (Bamford et al., 2004; Crane et al., 2012; Horn et al., 2007; Howe et al., 2014; Rose et al., 2012; Rose & Thornicroft, 2010; Stalker et al., 2005; Vernooij-Dassen et al., 2006). Furthermore, the vast majority of service-user perspective literature is qualitative, quantitative research in this area is very limited meaning there is a considerable shortage of statistically generalisable information

(Parker et al., 2014; Perkins et al., 2018). The current study builds on existing research by developing and validating a self-report measure of the impact of mental health diagnoses on recipients, such a measure does not currently exist.

Hayne (2003) notes the scarcity of studies that attend specifically to the experience of being given and living with a psychiatric diagnosis, many studies on diagnosis do not distinguish between this and the experience of psychological distress/disorder. The current study focuses exclusively on the diagnosis itself in as much as it can be isolated.

Perkins et al. (2018) note that service user experience studies predominantly focus on a single diagnosis. Although this affords an in-depth focus on individual disorders, it means that comparison of diagnosis impact between people with different diagnoses is more difficult and less accurate. This study will allow comparison across a variety of disorders within a single sample.

2.5.2. Clinical applications.

It is anticipated that the measure which has been developed will be also be applicable to clinical practice. It is proposed for use as an assessment tool by therapists and services to gain insight into the client's relationship with their diagnosis. The scale may also be appropriate for use during therapy, if a client receives a new diagnosis or their diagnosis becomes more salient in the therapeutic work. Overall, the aim of the measure is to empower diagnosis recipients/service users and facilitate discussions with professionals about their experience of disorder labels. As evidenced by the literature on the topic, communication of and about diagnosis significantly affects service-user satisfaction.

It is expected that the current study will be of particular interest to counselling psychologists as they become more embedded in the public healthcare system where diagnosis dominates (Douglas, 2010). They may be expected to communicate diagnoses

and/or work with patients who have received a diagnosis. Counselling psychologists have reported discomfort in working with diagnosis due to under-confidence and professional incongruence with psychiatric classification (Davies et al., 2017) suggesting they may benefit from a tool which enables them to work with diagnosis in a more relational and humanistic way.

Chapter 3:

Methods and Results

3.1. Ethical approval

Ethics applications pertaining to the item pool development and the scale development and validation phases were submitted for consideration by the University of Roehampton Ethics Committee under the references PSY 16/236 and 16/237 and were approved according to procedures of said committee on 31/08/16 and 16/11/16 (Appendix B).

3.2. Epistemology

This study has undeniably positivist underpinnings in that it uses traditional quantitative scale development protocols (McEvoy & Richards, 2006). However, the overarching aims which led to this choice of methodology are not uncritically positivist. The intention of this study is to explore the real and tangible impact of psychiatric diagnosis, while this impact is also thought to be mediated by societal conceptualisations of psychological difficulty and distress. Therefore, the epistemological stance of the study is best described as critical realist.

3.2.1. Critical realism.

According to Phillips (1987) realism is, 'the view that entities exist independently of being perceived, or independently of our theories about them' (p. 205). Critical realism is a post-positivist approach which combines transcendental realism, the idea that mechanisms and entities exist regardless of our ability to access them using empirical methods, and critical naturalism, the position that transcendental realism is applicable to both natural and social sciences but the study of the latter must differ from that of the former by focusing on mechanisms causing social events (Bhaskar, 1975).

Critical realism holds the distinction between ontology and epistemology as central (Archer, 1998). This differentiation between the two means that within a critical realist stance, one can maintain a realist view of the world while also subscribing to the relativist idea that what is knowable about it is socially constructed and inherently bound to interpretation and subjectivity (Clark, 2008; Clark, Lissel, & Davis, 2008; Guba & Lincoln, 1994; Maxwell, 2012). In essence, it views what *is* as being independent of what can be *seen to be*. Therefore, not all that exists is discoverable by observation or enquiry. And although it is important to attempt to know more about the real nature of the world and its phenomena, what is known will inevitably be limited and influenced by the perspective of the researcher (Pilgrim & Bentall, 1999). Therefore, what is discoverable does not necessarily reflect a single, absolute truth (Maxwell, 2012). In this sense, the human lens will always exist between reality and what we can know of it. There is no direct or objective route available to us. Thus, the ontological position of critical realism differs from its epistemology. Critical realism combines ontological realism and epistemological relativism (Archer, 1998). This is viewed by many as providing a middle ground for researchers between the polarised positions of positivism and interpretivism (DeForge & Shaw, 2012; McEvoy & Richards, 2006). Like positivism, critical realism has a realist ontology. However, in terms of epistemology, positivism advances that reality is directly observable using the scientific method (Ackroyd, 2004). The goal of scientific enquiry is to uncover context-free universal laws which represent truths about the world (Hudson & Ozanne, 1988). In contrast, critical realism holds a relativist epistemology which is more aligned with that of interpretivism (Scotland, 2012).

Roy Bhaskar, the philosopher credited with the development of critical realism, proposes three layers of reality and being: the *real*, the *actual*, and the *empirical*

(Bhaskar, 1975). The real is made up of, sometimes imperceptible causal mechanisms that are responsible for the events which take place in the actual. The empirical domain represents our imperfect human representations and experiences of the real and the actual. Unlike positivism and interpretivism, the aim of critical realist research is not to unearth universal, general laws or to present ideographic accounts of context-bound phenomena, instead it endeavours to find some 'demi-regularities' and tendencies in the actual domain which may elucidate some of the causal mechanisms of the real (Hartwig, 2007; Lawson, 1999). Therefore, the route to the real is often thought to be via the actual. Critical realism ultimately aspires to provide explanations rather than truths or predictions, which are central to positivism (Bredo & Feinberg, 1982; Pocock, 2015). As seen above, critical realism places a heavy emphasis on causal mechanisms and critical realist research aims to provide a better understanding of these.

A key feature of philosophical paradigms is the extent to which they distinguish between natural and social sciences, as this influences research design and interpretation. Positivism does not differentiate between the two fields of science. Positivist research is often conducted within closed systems, under laboratory conditions with extraneous variables controlled for (Tolman, 1992). On the other hand, interpretivists make a clear distinction between the social and natural worlds, viewing the social realm as 'linguistically constructed' (Geertz 1973; Winch 1958). Interpretivist research generally focuses on the construction and interpretation of events or experiences rather than the truth or lack thereof of the accounts (DeForge & Shaw, 2012). Although critical realism views natural and social sciences similarly with regard to ontology, it distinguishes between the two in terms of how they should be studied, with the focus of social science research on causal mechanisms (Bhaskar, 1975). Critical realists view positivism's closed system approach to research as inadequate as

they conceptualise the world as a complex and intricate open system (McEvoy & Richards, 2006). They argue that closed systems research neglects or excludes the context that interacts with the target variable, being, or entity under normal circumstances and therefore the results are incomplete and cannot be applied to the open systems it was designed to investigate (Bhaskar, 1975; Collier, 1994). Prediction is a central aim of positivist research (Hudson & Ozanne, 1988), whereas critical realism acknowledges the impossibility of this in the social world. Instead, it proposes that with a rigorous examination of measurable products of causal mechanisms, it is possible to expand our knowledge of the *real* (Danermark, Ekstrom, Jakobsen, 2001).

Congruent with this aspect of critical realism, the current project endeavours to examine some of the underlying mechanisms which influence what impact a diagnosis has on someone's life. The study attempts to begin to uncover imperceptible causal mechanisms of diagnosis impact through the measurable constructs of the impact itself and variables which seem to affect how diagnosis is experienced. The current research comes from a critical realist position in that it holds the effect of diagnosis on individuals as real and tangible but acknowledges that it cannot be captured in a value-free, objective manner. Critical realism views science as a subjective endeavour which has strong social and linguistic influences (Gorski, 2013). This echoes my attitude in undertaking this research, I would like to increase the understanding of diagnosis and its effects but do not believe that the results will represent an objective or single truth about the phenomenon. However, every effort has been made to maintain rigorous processes in order to maximise the likelihood of a helpful measure of the impact of psychiatric diagnosis, to understand the dimensions of this construct, and the underlying causal mechanisms which give rise to it. In this sense, it is closely aligned with the fundamental aim of critical realist research in attempting to better understand

phenomena while holding explanations lightly and critically (Pilgrim & Bentall, 1999). The project adheres to critical realist methodological recommendations in that it was designed based on a research need, rather than a priori selection of a methodological approach (McEvoy & Richards, 2006). Sobh and Perry (2005) note that a two-phase design is optimal for realist research: framework is generated in the first stage and then tested in subsequent stages. In this respect, scale development and validation are naturally aligned with a realist epistemology.

Critical realism differentiates between structure and agency. Gorski (2013) writes that, 'Human agents are bio-psycho-social structures with emergent powers of intentionality. Conversely, social structures have agency, an agency that transcends and influences the intentions of the individual agents that co-constitute them' (p. 668). In essence, critical realism views structures as determining the level of agency of the individual in spite of the fact that structures are created, in large part, by human agents. Critical realist research can sometimes have emancipatory goals, involving increasing consciousness about structures which are seen to diminish agency (DeForge & Shaw, 2012; McEvoy & Richards, 2006). The current research aligns with this in having the central aim of empowering individuals and hopefully allowing them to have a greater sense of agency by thinking about the usefulness of their diagnosis, thereby becoming a subject in relation to the diagnosis rather than an object. That is not to encourage people with diagnoses to reject their diagnoses or challenge them thoughtlessly, but to consider them in an active way. The reification of diagnosis and its dominance within mental health services can at times lead to a sense of powerlessness in service users rather than one of collaboration and agency.

3.2.2. Summary.

In philosophical terms, this research is most closely affiliated with the critical realist tradition, which, in itself combines two positions that show divergence between ontology and epistemology. With the complexity of open systems in mind, the results of this scale development study and any output of the scale itself are considered to represent tendencies and explanations rather than laws and truths.

3.3. Design

This study was designed in accordance with standard measure development and validation protocols (DeVellis, 2017). It is comprised of five stages; item pool development, expert rating of items to refine the item pool based on item relevance and quality), Three Step Test Interviews (to determine the content validity of the scale) and psychometric exploration of factor structure, reliability, and validity of the scale.

The aim of the first two stages was to generate a set of relevant and well-formulated items and to determine their face and content validity. The purpose of the psychometric exploration was to establish and confirm the internal reliability, construct and criterion validity, establish the factor structure of the scale using exploratory factor analysis (EFA), and assess the differentiation based on strength of attitude/endorsement (in ability measures this is referred to as difficulty) and discrimination capability of the final scale items.

3.4. Study 1: Item Pool Development

3.4.1. Creation of the item pool.

The initial stage in the development of the Diagnosis Impact Scale (DIS) was the creation of an item pool. An inductive approach to scale development was used (Hinkin,

2005). This method is adopted if there is little existing theory available and involves examining the experience of the target population, generated by consulting with a sample of respondents, categorising said experience based on themes or key words which are then used to compose individual items. Items for the pool were derived from a focus group and a review of service user and carer reports in qualitative interview studies on the impact of psychiatric diagnosis.

The inclusion criteria for this stage of the research were that individuals had to be 18 years of age or over, be experts in psychiatric diagnosis, and be either lecturers or students at the University of Roehampton (as specified in the application for ethical approval). Individuals were viewed as experts on psychiatric diagnosis on the basis of having received a diagnosis personally, having experience of clinical work with clients and patients with diagnoses, or a combination of these. Participants were recruited via emails (see Appendix C) to classmates of the researcher (third year PsychD students) and course lecturers. They self-selected by responding to the email and arranging to attend the focus group. The focus group was comprised of five students in their third year of the University of Roehampton Practitioner Doctorate in Counselling Psychology (PsychD) and one University of Roehampton PsychD visiting lecturer. The researcher did not enquire about the personal status of participants in relation to diagnosis but knew from prior personal communication that some participants had previously received diagnoses. It was considered important to capture the diagnosis recipient perspective in the item pool development. Participant demographic information is summarised in Table 1 below. The focus group was held at Whitelands College at the University of Roehampton. See Appendix C for the information sheet, consent form and debriefing form pertaining to this stage. The discussion was initially unstructured, with participants being asked to speak freely about their thoughts on the impact of

psychiatric diagnosis. Participants later asked that the research clarify which type of impact was being explored and the researcher posed some more directive questions to the group toward the end of the discussion (e.g. Do you think that having a diagnosis affects career prospects?). Thematic analysis of focus group data suggested seven different areas of life which can be affected by having a psychiatric diagnosis, these were: power, identity, emotion, help-seeking and treatment access, social life, employment and/or education. Focus group data and qualitative literature on service-user experience were used to inform the creation of items for seven subscales based on the themes above.

Table 1. Focus Group Participant Demographic Information

Age (mean, SD)	39.80 (12.50)
Gender (n, %)	
Female	3 (60%)
Male	2 (40%)
Other	0
Ethnicity (n, %)	
White British	2 (40%)
White Other Background	2 (40%)
Chinese or Chinese British	1 (20%)
Profession (n, %)	
Trainee Counselling Psychologist	4 (80%)
Researcher	1 (20%)

The first version of the scale asked participants to respond to items based on their experience of their diagnosis during the six months prior to participation. The aim of the time frame was to focus respondents on a recent period and give clarity to the scale. It was set at six months as it was thought to be long enough to allow for events/experiences mentioned in items to have occurred (e.g. a range of emotions and interactions with people and organisations) while adding precision. Scale items were created to suit one of two 5-point Likert response scales requiring participants to select their level of endorsement of statements (‘Strongly agree’ to ‘Strongly disagree’) or select the frequency with which they had a particular experience (‘Always’ to ‘Never’).

There was a total of 108 items in the item pool which were written based on the seven most prominent areas of diagnosis impact discussed in the qualitative literature reviewed and during the focus group discussion; impact on emotion (21 items, e.g. 'My diagnosis has made me feel broken'), identity (18 items, e.g. 'My diagnosis has made me think I am crazy'), help-seeking/receipt (19 items e.g. ' My diagnosis has helped me to access specialised care'), social life (23 items, e.g. 'I have been rejected by people due to my diagnosis'), power and control (15 items, e.g. 'My diagnosis has given me more power over my difficulties'), education (five items, e.g. 'My diagnosis has meant that changes were made to facilitate me in education/training'), and employment (seven items, e.g. 'My diagnosis has had a negative effect on my career').

3.4.2. Expert online rating.

The item pool was then refined in a process of 'expert rating' (Hinkin, 2005). This took the form of a questionnaire on the Qualtrics online survey platform. The inclusion criteria for this stage of the research were as above; individuals had to be 18 years of age or over, be experts in psychiatric diagnosis, and be lecturers or students of the University of Roehampton. A participation invite email was sent to members of the PsychD Year 3 (2016-2017) class who had not taken part in the focus group as well as all lecturers and academics connected to the PsychD programme (see Appendix D). All recipients of this email were known to be clinical practitioners either in-training or qualified. Again, participants were viewed as experts on psychiatric diagnosis on the basis of having received a diagnosis personally, working therapeutically with clients and patients with diagnoses, or a combination of these. Participants self-selected by following the survey link on the invitation email mentioned above. Sample characteristics are summarised in Table 2.

Table 2. Expert Online Rating Demographic Information

Age (mean, SD)	39.8 (11.87)
Gender (n, %)	
Female	7 (70%)
Male	3 (30%)
Ethnicity (n, %)	
White British	4 (40%)
White Other	4 (40%)
White Irish	1 (10%)
Caribbean	1 (10%)
Profession (n, %)	
Trainee Counselling Psychologist	2 (20%)
Psychologist	2 (20%)
Lecturer	2 (20%)
Researcher	1 (10%)
Researcher/Psychologist	1 (10%)
Administrator/Therapist	1 (10%)
Student	1 (10%)

Expert raters were asked to assess each item on its overall formulation/composition and relevance for inclusion in a scale aiming to measure the impact of psychiatric diagnosis. This was stated in the information sheet and the introduction to the online rating survey. See Appendix D for information sheet, consent form and debriefing form. Items were rated on a four-point Likert scale: 1='Definitely no, do not include in the survey', 2 = 'Probably no, do not include in the survey', 3= 'Probably yes, do include in the survey', and 4= 'Definitely yes, do include in the survey'. Although Hinkin (2005) suggests using a 5-point scale in item rating, a mid-range response option was considered unhelpful for the purposes of deciding on item inclusion. Each item was given a single score which represented the rating for both formulation and relevance of items, and there was a space for comments after each item to allow for general comments or re-formulation suggestions. Additionally, in some cases, items were phrased in two ways, with participants being asked to indicate a preference in the space provided. There were sixteen respondents in total. Partial responses were removed if participants rated less than ten items, there were six such

cases leaving ten complete responses. 71 out of 108 items had a mean rating of 3 or above. See Appendix D for online item rating scores.

3.4.3. Item selection.

The number of items was reduced following an analysis of the expert rating data. Based on raters expressing confusion at the change in response scale for some items (i.e. frequency rather than agreement), it was decided that one response scale should be used throughout the measure. It was agreed that all items with a mean rating of 3 or higher would be retained, with the exception of two items which were deemed unsuitable. One of these items was thought to be unclear and confusing while the other required participants to comment on beliefs others held about them. This was viewed as too far removed from participants' experience and required them to speculate about the thoughts of others. Also, one combined item (where participants were asked to choose between two versions of the same phrase) was split, meaning the number of items increased by one. Items with mean ratings lower than 3 were assessed on a case-by-case basis, there were 38 such items. Twenty-two of these were removed based on ratings and comments. Problems with these items were represented by four themes: complex/confusing wording, vague meaning, politically-loaded or emotional terminology, and items which would not be applicable to the majority of participants. Eleven items which were thought to address an important aspect of diagnosis impact, but according to comments, received low ratings due to poor formulation, these were re-worded and included in the scale. There were five items which were deemed to be well-formulated with clear language, relevant to their subscales, and representing an important aspect of diagnosis impact despite rating scores. In total, this left 85 items and the seven subscale (emotion, identity, power and control, help-seeking/receipt, social, educational, & employment) structure was retained.

3.4.4. Three-Step Test Interviews

The Three-Step Test Interview (TSTI) protocol (Hak, van der Veer, & Jansen, 2004) was used to examine the content validity of the Diagnosis Impact Scale. Following analysis of interview data, further filter/branching items were added to the scale to determine the applicability of certain items (those which related to other people knowing the participant's diagnosis, employment, and education items) to participants and direct them to the next section accordingly) which meant it was refined to between a minimum of 56 items (main scale excluding demographics and filter/branching items but including one item on the reason for not being engaged in employment or education) and a maximum of 82 items (including 'people who knew' items, employment, and education items but excluding filter/branching items). Thus, the number of scale items presented to a participant depended on whether others were aware of a participant's diagnosis, participant employment status, and current education or training engagement.

3.4.4.1. Piloting the Three-Step Test Interviews.

A pilot Three Step Test Interview was conducted for me to gain experience of using the protocol and ensure satisfactory delivery in participant interviews. The pilot interview was carried out in the CREST (Centre for Research in Social and Psychological Transformation) Clinic at the University of Roehampton with a CREST researcher who volunteered as a mock participant. The participant gave targeted feedback on her experience of the TSTI throughout the interview and general feedback on completion.

3.4.4.2. Three-Step Test Interview participants.

Two individuals volunteered to participate. Although more participants are required to satisfy data saturation guidelines (Hak, van der Veer, & Jansen, 2004), it was decided, due to time constraints, that data from the two interviews would be used.

Both participants were white females, aged 45 to 55. When asked their occupation, one identified as a teacher and the other as a lawyer. Their mental health diagnoses were bipolar II disorder and depression.

3.4.4.3. Measure.

The Three-Step Test Interview (TSTI) is a pre-test observation and interview protocol for evaluating self-report questionnaires under development (Hak, van der Veer, & Jansen, 2004). It has been assessed in a number of studies which indicate its efficacy in detecting response issues arising from discrepancies between intended meaning and interpretation of items (Bode & Jansen, 2013; Busse & Ferri, 2003; Hak, van der Veer, & Jansen, 2008; Hak, van der Veer, & Ommundsen, 2006; Jansen & Hak, 2005; Paap, Lange, van der Palen, & Bode, 2016). The method consists of an initial concurrent 'think aloud' stage which involves the participant verbalising their thoughts as they go through the measure, allowing the researcher to observe interpretative processes. This is followed by a focused interview enabling the researcher to pose targeted questions aimed at clarifying or elaborating on observational data and finally a semi-structured interview elucidating the participant's subjective experience of the questionnaire. The TSTI aims to yield specific information on survey completion by participants and general feedback on their experience of responding to the questionnaire. The researcher takes notes during the interviews and these, in addition to audio/video recordings are subsequently analysed.

3.4.4.4. Procedure.

Participant recruitment emails were sent to a small number of third sector mental health organisations as well as CREST Clinic clients and staff (Appendix E). Organisations were asked to post participation invites on their social media sites and websites, and to display posters where appropriate. Recruitment materials invited

individuals over 18 who had received a mental health diagnosis more than six months previously to volunteer for anonymous participation in the interviews.

Interviews were held at the University of Roehampton. For standardisation purposes, both interviews were carried out using the researcher's laptop. In both cases, researcher and participant sat at a table facing the computer, the researcher sat a little further back to enable autonomous responding during the think aloud phase. The researcher explained the interview protocol including an outline of the instructions for each section and the objective of the TSTI. Participants were reminded that interviews would take up to an hour and would be audio recorded. Interviews began with a verbal outlining information sheet and consent form (see Appendix E), highlighting anonymity, right to withdraw without explanation, and participants were asked to alert the researcher if they experienced distress during the interviews. Upon completion of the consent form, the recording commenced, and they were invited to answer some demographic questions.

A detailed explanation of the concurrent think aloud stage was given including a sample exercise. Participants were instructed to verbalise any thoughts they had regarding scale items without giving justifications or explanations, they were asked to proceed as if the researcher were not in the room and told that they did not need to react to each item, only those that evoked a response in them. They were reminded that the researcher would be making notes on their behaviours and verbalised thoughts during completion. Both participants wanted to do the sample exercise before beginning the interview, this involved counting through the windows in their home while verbalising the process (Willis, 2004). The researcher provided feedback during the task such as, 'you're doing very well' and 'don't worry, you needn't explain your thoughts, pretend I'm not here'. If they felt they understood the proposed task, we began the interview.

Participants were asked to read questions aloud before selecting responses. Each participant was presented with a minimum of 74 scale items (comprised of randomised items from emotional, identity, power and control, help-seeking/receipt, and social impact subscales), with six additional items on employment and five additional items on education, if applicable. At the end of this phase, the researcher empathised with any expressions of fatigue or finding the process strange and suggested that the following steps should be quicker and less taxing.

The next phase involved enquiring about any hesitations during the think aloud segment and asking participants to expand and/or clarify anything that seemed unclear. The last phase was a more focused and in-depth enquiry on their impression of the scale followed by broad questions on their experience of responding. Finally, participants were invited to give feedback on the process and ask questions. Participants received a debriefing form (see Appendix E) with the ID number they generated previously, were asked to provide this number should they wish to withdraw from the study, and kept a note of the number on interview notes.

Interviews were transcribed before a brief thematic analysis, highlighting elements which proved challenging during the TSTI. Problematic items were modified (22 items) or removed (five items) and two items were added following qualitative analysis (Crabtree & Miller, 1999; Willig, 2013), see next section for further discussion of results.

3.4.4.5. Three-Step Test Interview results.

The semi-structured interview stage of the Three Step Test Interviews (TSTI) indicated some general issues with the structure and content of the scale. Both participants found that the time frame given in the instructions was problematic and that many items were not applicable to the 6 months prior to the interviews, as they related

to experiences which participants had not had during this time frame, but had had since diagnosis. In addition, they reported that as they progressed through the survey, they forgot to take the time frame into account when responding to items. On reflection, it was decided that although the six month time frame had the potential to add clarity and specificity to the scale, it was only helpful if participants remembered to answer each item in relation to the previous six months. A further benefit was that removing the time frame would make scale items more widely applicable across participants. Additionally, it was thought to increase the likelihood of uniform responding i.e. avoid participants answering initial items with regard to the past six months and later ones without considering the time frame.

One of the participants also found she was inclined to answer items as if they pertained to the impact of her mental health issues rather than the mental health diagnosis itself. She suggested that the focus on the diagnosis rather than experience of mental health difficulties be emphasised in the introduction to the scale. This point was added as a stand-alone paragraph in the introduction to the scale.

One participant, although employed, found that the employment subscale items did not pertain to her as neither her employer nor her colleagues were aware of her diagnosis and the items mainly related to treatment of the participant in light of their diagnosis being known. Similarly, one of the participants noted that many of the social impact subscale items would not be relevant if people in her life had not been told about her diagnosis. In order to address these problems, a ‘Not applicable’ response option was added to all employment and education subscale items and a branch/filter item was added which directed participants who had disclosed their diagnosis to others to the social impact items which pertained to awareness of diagnosis by those in their lives apart from mental health professionals.

During the ‘think aloud’ stage and the focused interview, item-specific problems were observed and discussed. The majority of these related to items being too general or ambiguous, having two clauses resulting in the participant having a different response to each part of the item and affective language in items evoking an emotional response rather than a response to the item itself. Items that were too general were edited to increase specificity. One item with multiple elements was split into two separate items, ‘I have kept my diagnosis a secret from most people in case they treat me differently’, was split into, ‘I have kept my diagnosis a secret', and, 'I have worried that people would treat me differently because of my diagnosis’. One item, ‘My diagnosis has made me feel judged’, was added. Twenty items were amended to increase clarity and specificity. Emotionally-charged language items were amended in order to elicit a response to the entire item. Five items were removed and two were added. See Appendix E for TSTI results by item.

3.5. Study 2: Psychometric Exploration

Following analysis of TSTI data, the main scale consisted of 55 items (including items from the emotional, identity, power and control, help-seeking/receipt, and social subscales), 16 of the items pertaining to the social impact of diagnosis were contained in a separate subscale only displayed to those who indicated that they had told others about their diagnosis and there were also separate subscales on impact on employment (six items) and education/training (five items). The total number of items subsequent to the TSTI was 82, with participants asked to answer fewer items if certain subscales were not applicable to them. See Appendix F for scale items.

The aim of this psychometric exploration was to investigate the reliability, validity and factor structure of the Diagnosis Impact Scale. A large number of participants was required for this phase of the research.

3.5.1. Psychometric exploration study participants.

3.5.1.1. Sample size.

Sample size recommendations for exploratory factor analysis in measure development vary significantly, some suggest basing the number of participants on the number of items (Tinsley & Tinsley, 1987) while others also believe that the number of anticipated factors should determine sample size (Worthington & Whittaker, 2006). Comrey and Lee (1973) indicate that a sample of 200 is adequate for a scale of 40 items. According to a more recent study, Comrey and Lee (1992), a sample of 100 participants is poor, 300 is good and 1000 is excellent. Guadagnoli and Velicer's (1988) findings suggest that sample size is secondary to the strength of factor loadings and deem factors to be reliable if they consist of four or more loadings of .6 or greater. Field (2018) concludes that a sample of 300 or more should yield a stable factor structure.

It is possible to estimate sample size adequacy using the Kaiser-Meyer-Olkin (KMO) statistic which ranges from 0 to 1. In the exploratory factor analysis of the current study, the KMO value was .953. According to Kaiser and Rice (1974), values greater than .90 are considered 'marvellous'. Although the total sample analysed was 315, as cases were excluded listwise (meaning that if a participant failed to respond to any main scale item their data was not used in the factor analysis), the sample size for this analysis was 248. This was because 67 participants did not answer one or more of the DIS items.

3.5.1.2. Target population.

The inclusion criteria for the online psychometric exploration study participants were: individuals aged 18 or over who had received a mental health diagnosis from a healthcare professional in the past. The survey included an item asking participants if they were mental health professionals. Although these individuals were included in the study, it was thought prudent to identify mental health professionals as they may have views on diagnosis which are influenced by their professional lives as well as their own experience of diagnosis, resulting in a dual-experience. Although this would not be problematic, it was important to ascertain the lay/mental health professional ratio in order to determine the relevance of results to diagnosis recipients who are not mental health professionals. Examples of mental health diagnoses were not given in recruitment materials or the survey itself for two reasons. The first was to allow individuals who felt they had a mental health diagnosis to participate rather than stipulating what diagnoses fell under the term 'mental health diagnosis' and secondly, it was thought that examples may be interpreted as a list of disorders included in the study. Moreover, there is no widely accepted definition of psychiatric/mental health diagnosis and definitions of 'mental disorder' vary between classification manuals. A broad guideline used was to include diagnoses included in the DSM and ICD manuals or variations on same. A time frame within which participants had to have received their diagnosis was not stipulated as this was experienced as unhelpful by TSTI participants, with some items being relevant to the past six months and others being relevant more generally. In addition, there was a concern that participants may forget the time frame as the survey progressed and it was not possible to display intermittent reminders on the Qualtrics platform as items were randomised.

3.5.1.3. Recruitment of participants.

The target sample size for this study was a minimum of 300 participants. In an effort to achieve representative sampling, 121 non-NHS mental health (and related) organisations were approached including those that work specifically with men, ethnic minorities, older adults and LGBTQ individuals. Organisations were emailed and contacted by telephone and asked to post a participation invite on their social media pages and/or websites, send invites to staff and service users/contacts and/or display posters in branches. In addition to this, convenience and snow-ball sampling was used, with the research team (Niamh O' Connor, Prof Mick Cooper and Dr Gina Pauli) sending email invites to colleagues and posting participation invites (see Appendix G) on Facebook, Twitter, and LinkedIn social media platforms (both personal and CREST) . The survey link was posted on social media numerous times before a final post with a participation deadline was shared.

An online participant recruitment platform, Call for Participants, was also used. A customised 'study page' was set up which was displayed on the Call for Participants website and participant members were notified by email. The response rate was 13% (372 individuals visited the study page and 51 of these participated in the survey). It was not possible to estimate response rates for all sampling as the majority of participants did not specify how they had heard about the study in their responses, despite being invited to give the source of the survey link i.e. to give the name of the organisation whose social media page it was shared on or the organisation who sent them a participation invite email. It is possible that the recruitment methods used could have attracted a community bias (Morgan, 2008), however, the wide dissemination of recruitment materials across many organisations may have mitigated this.

Organisation approach emails (Appendix G) included details about the purpose of the study, inclusion criteria and how they might be able to facilitate participant recruitment should they so wish. A copy of the participant information sheet (Appendix G) was attached to these emails. In addition to the above, this included details of what participation would involve (survey duration and an outline of the questionnaire), contact details of the research team, information on confidentiality, right to withdraw and data storage as well as a warning about potential distress associated with participation.

3.5.1.4. Participant demographics.

A total of 387 people accessed the survey and responded to at least one item. Three individuals (0.77%) were unable to proceed with the survey as they stated that they were under 18 years of age. Four individuals (1.03%) did not consent to participate and were therefore unable to proceed with the survey. Similarly, 38 individuals (9.82%) stated that they had not received a mental health diagnosis and, as above, were not eligible to respond to the survey. 342 individuals who accessed the survey were eligible to participate. Of these, 27 (7.89%) participants did not answer any of the DIS items and were therefore excluded from all analyses. 315 participants were included in the analysis. Of these, 254 (80.63%) were females and 55(17.46%) were males and 6(1.90%) selected 'Other' for the gender item. Participant age ranged from 18 to 75 with a mean age of 35.59 (SD= 12.83). 313 participants responded to the 'Country of residence' item. Of these, the majority (80.83%) were resident in the United Kingdom at the time of survey completion. Demographic information is displayed in Table 3 below.

Table 3. Psychometric Exploration demographic information

Age (mean, SD)	35.59 (12.83)
18-39 (n, %)	197 (62.74%)
40-59 (n, %)	102 (32.48%)

60+ (n, %)	15 (4.78%)
Gender (n, %)	
Male	55 (17.46%)
Female	254 (80.63%)
Other	6 (1.90%)
Ethnicity (n %)	
White British	212 (67.30%)
White Irish	35 (11.11%)
White Other Background	40 (12.70%)
White and Black Caribbean	3 (0.95%)
Mixed White and Asian	2 (0.63%)
Other Mixed Background	2 (0.63%)
Indian	4 (1.27%)
Other Asian Background	3 (0.95%)
Caribbean	2 (0.63%)
African	4 (1.27%)
Other Black Background	2 (0.63%)
Chinese or Chinese British	1 (0.32%)
Other Ethnic Background	3 (0.95%)
Country of Residence	
United Kingdom	253 (80.83%)
Ireland	23 (7.35%)
United States	19 (6.07%)
Other	18 (5.75%)
Diagnosed by (n, %)	
Psychiatrist	142 (45.08%)
Counsellor	10 (3.17%)
Psychotherapist	12 (3.81%)
Psychologist	18 (5.71%)
General Practitioner (GP)	114 (36.19%)
CBT Therapist	8 (2.54%)
Other	8 (2.54%)
Unknown	3 (0.95%)
Time since diagnosis (mean no. of years, SD)	7.47 (7.60)
Helpfulness of Diagnosis (n, %)	
Very Helpful	62 (19.68%)
Helpful	126 (40.00%)
Neither Helpful nor Unhelpful	61 (19.37%)
Unhelpful	31 (9.84%)
Very Unhelpful	30 (9.52%)
Don’t know	5 (1.59%)
Multiple Diagnoses (n, %)	
Yes	194 (61.59%)
No	111 (35.24%)
Don’t know	10 (3.17 %)
Number of diagnoses- if multiple (mean, SD)	2.92 (1.54)
Correct Diagnosis (n, %)	

Yes	205 (65.08%)
No	57 (18.10%)
Don’t know	53 (16.83%)
Currently in Treatment (n, %)	
Yes	195 (61.90%)
No	115 (36.51%)
Don’t know	4 (1.27%)
Treatment Helpfulness (n, %)	
Very helpful	65 (20.63%)
Helpful	109 (34.60%)
Neither helpful nor unhelpful	47 (14.92%)
Unhelpful	22 (6.98%)
Very unhelpful	25 (7.94%)
Don’t know	19 (6.03%)
Formal assistance at work or in education (n, %)	
Yes	76 (24.13%)
No	172 (54.60%)
Don’t know	5 (1.59%)
N/A	62 (19.68%)
Mental health professional (n, %)	
Yes	80 (25.40%)
No	232 (73.65%)

3.5.3. Measures.

In this section I will discuss the questionnaires used in the psychometric exploration study. I will begin by briefly introducing the measure under development, the Diagnosis Impact Scale (DIS). This will be followed by an outline of socio-demographic and criterion validity items, which were presented to online survey participants before the DIS, and their role in the validation of the DIS. Finally, I will summarise the validity measures used in the study. Construct validity was assessed using the Patient Feedback on Consultation Skills Questionnaire, Satisfaction with Life Scale and a single-item measure of diagnosis helpfulness for convergent validity while the Social Desirability Scale-17, CORE-10, and Positive and Negative Affect Schedule were included to determine discriminant validity.

3.5.3.1. The Diagnosis Impact Scale (DIS).

The purpose of the scale under development, the Diagnosis Impact Scale, is to measure the effect of diagnosis on recipients, as perceived by them. The scale begins with response instructions including a definition of 'mental health diagnosis', 'mental illness' (as this term is included in the definition of mental health diagnosis), and a reminder that the items relate to the diagnosis itself rather than the experience of mental health difficulties. Participants are asked to indicate their level of agreement with a series of statements (e.g. 'My diagnosis has helped me to feel better about myself', 'I have felt that my diagnosis defines me' and 'My diagnosis has given me greater access to professional help') on a 5-point Likert scale ('Strongly agree', 'Somewhat agree', 'Neither agree nor disagree', 'Somewhat disagree', 'Strongly disagree'). In the first version of the scale following the TSTI, which was used in the psychometric study and consisted of 82 items, participants who had revealed their diagnosis to others, were in employment and/or education/training were asked to complete additional subscales related to diagnosis impact in these areas. See Appendix H for item count at each stage of scale development and Appendix F for DIS items used in the online psychometric survey.

3.5.3.2. Criterion validity items.

These items were presented to participants before the DIS in the online survey. They were asked to state their diagnosis and from whom the received it. They were also asked if they were receiving treatment because of their diagnosis and how helpful they found said treatment. This section of the survey also included an item on receipt of formal assistance in employment or education/training because of diagnosis and perceived accuracy of diagnosis. This last variable is slightly different from 'diagnosis fit' which was the concept used by Perkins et al. (2018). It was important in the current

research, given that it was an online quantitative survey, that the item was very precise and clear. It was thought that the idea of diagnosis fit may be difficult to adequately explain in text form and that the item, 'Do you feel you have received the correct diagnosis?', was clearer while being sufficiently similar conceptually. Participants were asked if they were mental health professionals to help determine the generalisability of results across non-healthcare professionals. See Appendix I for individual items.

Criterion validity variables were selected on the basis of associations with diagnosis impact indicated in previous literature. In order to establish criterion validity of the DIS, relationships between diagnosis impact and the variables above were expected to be in line with findings of previous research (detailed in Chapter 2).

3.5.3.3. The Patient Feedback on Consultation Skills Questionnaire (PFC).

The original application of this scale is to look at patients' experience of doctor-patient communication. An amended version of this questionnaire was included in the survey (with prior permission from the lead author of the PFC) to assess participant satisfaction with the communication of their diagnosis, see Appendix J for amended PFC, to investigate the convergent validity of the DIS. Research suggests that the quality of this communication can significantly affect how the diagnosis is experienced (Abbott et al., 2012; Hackett, Shaikh, & Theodosiou, 2009; Howe et al., 2014; Laird et al., 2009; Mansell and Morris, 2004; Osborne & Reed, 2008; Perkins et al., 2018; Pitt et al., 2009). It is anticipated that participants with high communication satisfaction scores will also report high positive impact of diagnosis. Conversely, those with low communication satisfaction scores are expected to report a more negative impact of diagnosis.

The PFC is a 16 item self-report measure of patient satisfaction with doctor-patient communication (Reinders, Blankenstein, Knol, de Vet, & van Marwijk, 2009).

The scale was developed by adding additional items to the previously validated Patient Perception of Person Centredness questionnaire (Stewart, 2003). It has a 4-point response scale ('Completely', 'Mostly', 'A little', 'Not at all') and is intended to be completed on the same day as the consultation. The questionnaire amendments for the current study were; replacing 'doctor' with 'healthcare professional' and removing the timeframe 'today' from any items that included it (See Appendix N). In addition, brief instructions were added before the first item in lieu of the original introduction; 'Please answer the following with reference to the communication of your diagnosis. If you have received more than one mental health diagnosis please answer the following questionnaire on the one which you stated at the beginning of this survey'. The PFC was found to have high internal consistency (Cronbach's alpha= .89) and good validity with a sample of 222 Dutch general practice medical patients (Reinders, Blankenstein, Knol, de Vet, & van Marwijk, 2009). Construct validity was investigated by comparing the new items of the PFC with PPPC items which gave a correlation of .97, this was thought to show that both scales measured the same construct.

3.5.3.4. Satisfaction with Life Scale (SWLS).

This is a five item measure with a 7-point response scale ('Strongly agree'-'Strongly disagree') measuring overall life gratification (Diener, Emmons, Larsen, & Griffin, 1985), see Appendix K for full scale. The scale showed good reliability (Cronbach's alpha= .87) with a sample of 176 undergraduate students at the University of Illinois. Test-retest reliability was also high, with a correlation of .82. The SWLS was compared with ten subjective wellbeing measures including the Rosenberg Self-Esteem Scale (Rosenberg, 1965) and the neuroticism scale of the Eysenck Personality Inventory (Eysenck & Eysenck, 1964). Discriminant validity was indicated by a very low correlation with the Marlowe-Crowne Social Desirability measure (Crowne & Marlowe,

1964). Moderate to strong correlations with all measures except the Affect Intensity Measure indicated good convergent validity. Comparison with personality measure subscales suggests that life satisfaction is associated with being 'well adjusted' and is not linked with pathology. The SWLS was included in the scale development survey to investigate the convergent validity of the DIS. It was decided that satisfaction scales would be most comparable the DIS and therefore helpful in assessing convergent validity. The SWLS was chosen as it is a broad satisfaction measure which would be applicable to all participants. Satisfaction scales relating to mental health were found to be too specific, often naming service, clinician, or treatment type. No satisfaction scale on psychiatric diagnosis was found and as discussed in Chapter 2, there is no published scale on the impact of psychiatric diagnosis. A medium to large correlation was expected between diagnosis impact and life satisfaction.

3.5.3.5. Single-item diagnosis helpfulness measure.

As discussed above, as there is no measure of the impact of psychiatric diagnosis or satisfaction with same, convergent validity scale options were limited. A single item was included with socio-demographics, asking participants to consider how useful they found their diagnosis: 'Overall, have you found having a mental health diagnosis (if you have received more than one please answer about the one stated in the previous question) Very helpful? Helpful? Neither helpful nor unhelpful? Unhelpful? Very unhelpful?'. This item contributed to the convergent validity investigation in the absence of suitable previously validated scales. A large correlation was anticipated between diagnosis impact and diagnosis helpfulness.

3.5.3.6. Social Desirability Scale- SDS-17.

The SDS-17 is a 17 item shortened version of the Marlowe-Crowne social desirability scale (Crowne & Marlowe, 1960) which measures response bias in which

participants select the answers they think will be viewed most favourably by others (see Appendix L). It has a 'True'/'False' response format and contains seven reverse-coded items. It has been found to have satisfactory internal reliability in two studies, Stober (1999) found a Cronbach's alpha of .72 using a sample of students and then .80 using a 179 participant community sample with a greater age range (18-89) (Stober, 2001).

Stober (2001) used a sample 76 students from the University of Greifswald to investigate the convergent and discriminant validity of the SDS-17 by comparing it with the Eysenck Personality Questionnaire (EPQ; Eysenck & Eysenck, 1991; German version: Ruch, 1999). In addition, a separate sample of 84 students from the same university was used to compare the scale with the Sets of Four scale (Borkenau & Ostendorf, 1992) for convergent validity and the Five Factor Inventory (Costa & McCrae, 1992; German version: Borkenau & Ostendorf, 1993) for discriminant validity.

It was found to have adequate concurrent validity when compared with the EPQ lie scale with a correlation of .60 and a correlation of .52 with the social desirability measure on the Sets of Four. It also showed good discriminant validity with the neuroticism (-.09), extraversion (-.07) and psychoticism (-.16) scales of the EPQ and the Five Factor Inventory there were non-significant correlations with extraversion (-.12), openness to experience (.14), agreeableness (.03), however, there was a highly significant negative correlation with neuroticism (-.49) and a significant correlation with conscientiousness (.22) (Stober, 2001). The scale was included in this study to assess the vulnerability of the DIS to response bias. Therefore, a small or non-significant correlation was expected with the DIS.

3.5.3.7. CORE-10.

This is a ten item scale with a 5-point response scale ('Most or all the time', 'Often', 'Sometimes', 'Only occasionally', 'Not at all') measuring psychological

wellbeing. It is a short version of the CORE OM (Evans et al., 2002), see Appendix M for scale. The scale was developed using a total sample of 5821 UK participants from four different datasets (a primary care sample, the Medical Research Council Enhanced Care for Depression trial, a sample from the Office of National Statistics, and an occupation health service sample). It was found to have high internal consistency (Cronbach's alpha=.90). The scale was also demonstrated to have good convergent validity when compared with the CORE-OM (Cronbach's alpha=.94) using a clinical sample and .92 using a non-clinical sample, correlations with the Brief Symptom Inventory, Symptom CheckList-90-R, Clinical Interview Schedule-R, Beck Depression Inventory, Beck Depression Inventory II, Personal Health Questionnaire, and the Beck Anxiety Inventory ranged from .56 to .81. This measure was included in the survey as part of the discriminant validity investigation, to assess the extent to which diagnosis impact was affected by level of psychological distress. A small or non-significant correlation was expected with the DIS

3.5.3.8. Positive and Negative Affect Schedule (PANAS).

The PANAS (Watson, Clark, & Tellergen, 1988) is a self-report measure of positive and negative affect comprised of 20 items, ten negative and ten positive affect items and respondents are asked to indicate the extent to which they felt each emotion in a given time frame on a 5-point response scale ('1= Very slightly or not at all', '2=A little', '3=Moderately', '4=Quite a bit', '5=Extremely'), see Appendix N for scale. It was used as a measure of discriminant validity in the current study. The time frame used was 'in the past week'. It was developed with a total sample of 4,217 consisting primarily of American students. Internal consistency was high, with Cronbach's alphas ranging from .86 to .90 for positive affect (PA) and .84 to .87 for negative affect (NA) depending on the time frame used in instructions (at the present moment, today, past

few days, past few weeks, past year, in general). Convergent validity was shown to be very good with correlations above .90 while discriminant validity correlations were low. In a UK study with 1003 non-clinical adults Crawford and Henry (2004) found the measure to have high reliability (Cronbach's alpha of PA= .89, and Cronbach's alpha of NA=.85) and good validity. The PANAS was included in the survey as part of the discriminant validity analysis, to investigate the potential contamination of DIS results by inherent positivity or negativity of participants and also level of emotional reactivity. It was anticipated that the PANAS would have a small or non-significant correlation with the DIS.

3.5.4. Procedure.

The psychometric exploration survey was posted on the online survey platform, Qualtrics (2019). Participants followed the survey link included in social media posts, emails and on posters. Firstly, they were presented with an information sheet as described above which participants were advised to print as it contained contact details of the research team as well as helplines should distress occur during participation and before completion of the survey. This was followed by a consent form with further information on the voluntary nature of participation, confidentiality, and data storage (Appendix G) which required tick-box confirmation that they were over 18 and understood the consent statement prior to proceeding with the survey. If they selected 'no', they were directed to a debriefing form explaining the reason for survey termination. Participants who consented were directed to demographics items followed by instructions on completion of the DIS. They were then presented with the main scale items and participants who had disclosed their diagnosis to others answered additional social impact items. Participants engaged in employment and/or education/training were invited to respond to items on these and those who were not engaged in either

employment or education/training were asked to respond to an item on the effect of their diagnosis on this. They were then presented with some validation measures (Social Desirability Scale-17, CORE-10, Satisfaction with Life Scale, Positive and Negative Affect Scale) and an amended version of the Patient Feedback on Consultation Skills Questionnaire, used to measure satisfaction with communication of the diagnosis.

Participants then viewed a debriefing form (Appendix G) which contained the ID number they had generated at the beginning of the survey and included contact details for the research team as well as helpline numbers. They were also encouraged to print this form. Some minor amendments were made to the information sheet, consent form, demographics items and the introduction to the scale shortly after data collection began (Appendix O). Data remained on the Qualtrics platform until collection was complete and was then downloaded to the statistics programme, SPSS, for analysis.

3.5.5. Outline of the study.

3.5.5.1. A priori aims.

i. To develop a reliable self-report measure of psychiatric diagnosis impact on recipients: the Diagnosis Impact Scale (DIS).
ii. To validate the DIS.

3.5.5.2. Hypotheses.

In light of the research findings detailed in Chapter 2 I expect that:

i. Participants with diagnoses of personality disorders and schizophrenia experience their diagnosis as having more negative impact than other diagnoses in terms of practicality and emotional effects (Angermeyer, Beck, Dietrich, & Holzinger, 2004; Crisp, 2004; Ellison, Mason, & Scior, 2013; Howe, Tickle, & Brown, 2014; Perkins et al., 2018).

ii. Those who believe they received the correct diagnosis experience diagnosis as more helpful than those who feel their diagnosis is incorrect, as existing research suggests than perceived diagnosis fit is associated with a more positive experience of diagnosis (Bilderbeck et al., 2014; Highet et al., 2009; Horn et al., 2007; Laird et al., 2009; Perkins et al., 2018; Rose & Thornicroft, 2010).

iii. Participants receiving treatment because of their diagnosis view their diagnosis more positively than those who are not. Additionally, those who also find this treatment helpful are likely to experience more of a positive impact of diagnosis than those who do not feel they are receiving helpful treatment. These hypotheses are based on findings which suggest that diagnosis is experienced as helpful when it is associated with functional value (Perkins et al., 2018).

iv. Participants receiving formal assistance in employment/education/training (if applicable) as a result of their diagnosis experience more positive impact of diagnosis than those not receiving such assistance. This is based on research which indicates that those who experience practical benefits of their diagnoses find them more helpful (Perkins et al., 2018).

3.5.6. Results of psychometric exploration study.

3.5.6.1. Outline of the analysis.

Content validity.

This was established through the processes of item generation and selection, and TSTI interviews.

Exploratory factor analysis.

A principal component analysis was carried out to determine the factor structure of the scale being developed and to examine the relationship between scale dimensions.

Oblique rotation was used as there was no pre-determined theory on factor structure. The scree plot, eigenvalues and percentage of variance explained by factor solutions generated were reported as well as item loadings from the pattern matrix.

Two-parameter item response theory analysis.

Item response theory (IRT) is a set of statistical techniques/frameworks sometimes drawn upon in the development of scales measuring a range of variables including ability and attitudes (Steinberg & Thissen, 2013). It was originally developed for and applied to mathematical ability testing and is now commonly used as an alternative to or in conjunction with classical test theory in psychology and other disciplines (de Ayala, 2009). It differs from classical test theory in that it investigates scales at unit/item level rather than examining the scale/subscale as a whole and the relationships between items therein (de Ayala, 2009; Kline, 2000).

In the case of the IRT analysis conducted in this study, the two parameters items were tested against were discrimination and 'difficulty'. In its original context of IRT, mathematical ability testing, difficulty referred to how simple or complicated a question was. Difficulty per se does not apply in the context of an endorsement/agreement response scale, therefore the term is used in this context to adhere to conventions of the IRT model but refers to degree of endorsement.

Following the exploratory factor analysis, the scale under development was subject to a two-parameter IRT analysis to assess the differentiation between attitude strength/level of endorsement and discrimination ability of items. The analysis was carried out by a statistician and lecturer at the University of Roehampton, using Mplus version 6.12 software (Muthén & Muthén, 2010). This analysis was included in the study as it was thought to contribute to the rigour of the scale development process by examining item-level psychometric properties.

Reliability.

Internal reliability of each DIS dimension, indicated by the exploratory factor analysis, was assessed using Cronbach's alpha values with 95% Confidence Intervals (CI) reported. Effects on internal consistency were considered when deciding on item deletion following factor analysis.

Construct validity.

Convergent validity was investigated by examining the correlations between the DIS and the PFC, SWLS and the single-item diagnosis helpfulness measure. It was anticipated that these correlations would be medium to high, based on Cohen's (1988) correlation coefficient effect size guidelines. Discriminant validity was tested by looking at correlations between the DIS and the SDS-17, CORE-10, and PANAS. Correlations between the DIS and these measures were expected to be low.

Criterion validity.

Associations were expected between impact of diagnosis and diagnosis fit/perceived accuracy (Bilderbeck et al., 2014; Highet et al., 2009; Horn et al., 2007; Laird et al., 2009), diagnosis 'type' (Angermeyer, Beck, Dietrich, & Holzinger, 2004; Crisp, 2004; Ellison, Mason, & Scior, 2013; Howe, Tickle, & Brown, 2014; Perkins et al., 2018), receipt of helpful treatment as a result of diagnosis, and receipt of formal assistance in employment/education/training (Perkins et al., 2018). Dichotomous variable associations were tested using t-tests while continuous variable associations were assessed with bivariate correlations. Categorical variable relationships were investigated using analysis of variance (ANOVA).

Associations with socio-demographic variables.

Associations between diagnosis impact and age, gender, ethnicity, number of diagnoses, time since diagnosis, diagnosing professional, and mental health professional

status were investigated. There were no a priori hypotheses on the relationships with these variables, they were included for exploratory purposes. As above, t-tests, bivariate correlations, and ANOVA were used as appropriate based on variable type.

3.5.6.2. Results of descriptive statistical analysis of DIS items.

Main scale items had means between 1.55 and 4.11. Social impact scale items had means between 2.36 and 4.11. Employment impact item means were between 2.43 and 3.12 and educational impact item means were between 2.29 and 2.99 (See Appendix P for DIS descriptive statistics tables). The majority of items fell within the acceptable range, as recommended by Field (2018), for skewness (-1 to 1) and kurtosis (-2 to 2). Due to the large number of scale items (82), those with relatively high or low means, small standard deviations, and correspondingly high skewness or kurtosis values were removed from the analysis. There were five such items. These items were: 'Because of my diagnosis, I have felt my mental health difficulties are someone else's responsibility', 'My diagnosis has made me feel like I'm not the only one who feels like I do', 'My diagnosis has made me feel special', 'My diagnosis has helped me to look for information about my difficulties', and, 'I have worried that people would treat me differently if they knew about my diagnosis'. Six social impact items were included in the main scale section of the survey. Thirteen others were combined with three main scale items to form an auxiliary scale which participants were directed to if it applied to them based on whether or not people in their lives (other than healthcare professionals involved in their care) knew about their diagnosis. 258 (75.44%) participants indicated that others knew about their diagnosis, 12 (3.51%) indicated that nobody in their personal lives knew, and 72 (21.10%) participants did not respond to this item. Large numbers of participants (between 26.32% and 27.19%) did not respond to the social impact items. Six of these items had more than three 'Not applicable' responses. Due to

the large proportion of missing data and the high number of 'Not applicable' responses within this auxiliary scale, it was decided to opt for a more generally applicable scale by removing these 13 items. This left six social impact items within the main scale. One of these items had seven 'Not applicable' responses and one showed limited distribution of responses with a high mean and low standard deviation. The remaining four items were also removed as it was decided that the subscale had an insufficient number of items. There were very high rates of 'Not applicable' responses (between 16 and 37 per item) on the employment subscale despite the inclusion of a filter item before the scale which meant that it was only displayed to participants who indicated that it was relevant to them. This was also the case for the education impact subscale, with between 9 and 30 'Not applicable' responses per item.

3.5.6.3. Exploratory factor analysis results.

The Kaiser-Meyer-Olkin (KMO) measure of sampling adequacy was .95 and the Bartlett's test result was chi square (703) = 6638.38, with a significance of $p < .0005$, indicating that the data was suitable for factor analysis. When performing the exploratory factor analysis, cases were excluded listwise, meaning that any participants who did not respond to one or more items were excluded from this phase of the analysis.

The initial principal components analysis with Oblimin rotation was carried out, in which all components with eigenvalues of 1 or above were retained. There were 248 participants included in the analysis. This resulted in a five-factor solution that explained 63.18% of the variance, with a clear first factor accounting for 42.49% of the variance. The scree plot indicated a three-factor structure (Appendix Q). There was only one item loading on the fifth factor, so the five-factor solution was dismissed. Analyses of possible four and three factor solutions were conducted. The four factor solution had

one item loading on the fourth factor while the three factor solution had two items loading on the third factor. These potential solutions were disregarded due to the insufficient numbers of final factor loadings. A two-factor solution was the most parsimonious, with 20 items loading on the first component and seven on the second, accounting for 53.60% of the variance, with a low component correlation of -.24 indicating the existence of two discrete subscales. Items that correlated with either component at a level greater than .4 were taken as loading onto that factor and there were no complex items with secondary loadings above .3 (Nunnally & Bernstein, 1994). Again, the first factor accounted for 42.49% of the variance. Table 4 shows the item loadings on the two components. The first component was made up of items which appeared to relate to the function or utility of the diagnosis, both emotional, in how it helps the individual feel better, and practical, in terms of accessing help or coping with mental health difficulties. Together these items related to the positive and helpful aspects of diagnosis, thus the dimension was named the Helpfulness of Diagnosis (HoD) subscale. The second component consisted of items relating to a person's sense of identity, and internalisation of negative perceptions about people with mental health difficulties which is consonant with theoretical descriptions and definitions of self-stigma (Corrigan & Rao, 2012; Pescosolido & Martin, 2015). The second dimension of the DIS was therefore thought to reflect the self-stigma aspect of diagnosis impact and was named the Diagnosis-Related Self-Stigma (DRSS) subscale.

Table 4. Pattern Matrix with Oblimin Rotation

Item	Component	
	1	2
My diagnosis has helped me to understand myself better	.88	
I have been glad I received my diagnosis	.86	
Because of my diagnosis I have been hopeful that I can be helped	.85	
My diagnosis has given me more clarity about my difficulties	.85	.22

It would have been better if I had not been diagnosed	.84	
My diagnosis has given me more control over my difficulties	.83	
My diagnosis has made me feel I can be helped	.82	
My diagnosis has helped me to feel better about myself	.81	
My diagnosis has led to me being happier	.79	
My diagnosis has validated my experience	.79	
Thanks to my diagnosis I have been more willing to seek professional help	.77	
My diagnosis has given me hope	.76	
My diagnosis has been comforting	.75	
My diagnosis has made my difficulties worse	-.70	.30
My diagnosis has made me feel safe	.70	
My diagnosis has made me feel positive about the future	.69	-.23
My diagnosis has made me feel my mental health difficulties are taken seriously	.69	
My diagnosis has made me feel more 'normal'	.66	
My diagnosis has motivated me to find better ways of managing my difficulties	.63	
My diagnosis has given me greater access to professional help	.60	
I have felt that my diagnosis defines me		.69
My diagnosis has made me feel I am a weak person	-.23	.65
I have felt that my diagnosis means I am a 'damaged' person	-.27	.62
My diagnosis has made me think I am crazy	-.23	.62
I have felt I will always be stuck with my diagnosis		.62
My diagnosis has made me rethink my identity		.61
My diagnosis has made me more reliant on others		.53

In order to produce a succinct scale, it was desirable to remove items from the first factor. As the reliability of the scale was very high (Cronbach's alpha=.96), contribution of individual items to the internal consistency was not used as a criterion for item deletion. Two cross-loading items were removed ('My diagnosis has given me more clarity about my difficulties', and ,'My diagnosis has made me feel positive about the future') while one other complex item was retained ('My diagnosis has made my difficulties worse') to increase variation within the subscale as the majority of the items were positive in sentiment while this was negative. Two items were removed on the basis of similarity to others. The item, 'I have been glad I received my diagnosis', was removed as it related to the same concept as, 'It would have been better if I had not been diagnosed'. In the same vein, 'Because of my diagnosis I have been hopeful that I can

be helped', was removed as it was thought to resemble 'My diagnosis has made me feel I can be helped'. This left 16 items.

3.5.6.4. Two-parameter IRT analysis results.

Following preliminary item selection, a two-parameter IRT analysis was carried out in order to assess the differentiation between strength of attitude and discrimination ability of the two subscales. The adequate range for discrimination is between 0.5 and 2.5, with 0.8 to 2.5 considered to be good (Reeve & Fayers, 2005). Differentiation between strength of attitude (referred to as difficulty in ability measures) ranges from -3 to 3, with values below zero representing easy items and values above zero being more difficult (de Ayala, 2009). This indicated the removal of one item ('My diagnosis has given me more control over my difficulties') from the first subscale due to insufficient discrimination capacity (0.23) and level of differentiation between levels of endorsement (-5.62). See Table 5 and Table 6 below for results of the two-parameter IRT analysis.

Following this analysis, items on the first scale were re-evaluated based on content with a view to shortening it, and it was decided that a further three items should be removed; two were thought to address a similar aspect of diagnosis impact to other items. 'My diagnosis has made me feel I can be helped' and 'My diagnosis has given me hope' were similar, and the latter was kept, as it was deemed to be less ambiguous. In addition, 'My diagnosis has made me feel safe' was viewed as capturing the same emotion as 'My diagnosis has been comforting', again the latter was seen as less likely to attract multiple interpretations or confusion. One item was thought to be potentially semantically confusing ('My diagnosis has validated my experience') as it lacks precision (my experience) and the word 'validating' may have diverse interpretations. This left 12 items on the HoD subscale and 7 on the DRSS subscale. A reliability

analysis of each scale showed that the internal consistency could not be improved by removing any items (Appendix R). This was followed by an additional two-parameter IRT analysis. As seen below, all items fell within acceptable ranges for discrimination and differentiation based on strength of attitude (labelled 'Difficulty') according to the ranges given above.

Table 5. Results of Two-Parameter IRT on Helpfulness of Diagnosis Subscale

Item	Discrimination	Difficulty 1	Difficulty 2	Difficulty 3	Difficulty 4
It would have been better if I had not been diagnosed	0.82	-0.79	-0.22	0.46	1.75
My diagnosis has led to me being happier	0.79	-0.85	-0.27	0.40	1.87
My diagnosis has been comforting	0.82	-0.75	-0.18	0.65	1.88
My diagnosis has given me hope	0.78	-1.38	-0.69	-0.17	1.20
My diagnosis has made me feel my mental health difficulties are taken seriously	0.80	-1.60	-1.09	-0.35	0.87
My diagnosis has helped me to understand myself better	0.75	-0.65	0.09	0.96	2.43
My diagnosis has made me feel more 'normal'	0.86	-0.65	-0.15	0.63	1.65
My diagnosis has helped me to feel better about myself	0.75	-1.7	-0.94	-0.18	0.58
My diagnosis has made my difficulties worse	0.74	-1.20	-0.64	-0.26	1.10
My diagnosis has given me greater access to professional help	0.73	-1.79	-1.12	-0.51	1.19
Thanks to my diagnosis I have been more willing to seek professional help	0.66	-2.08	-1.49	-0.74	0.96
My diagnosis has motivated me to find better ways of managing my difficulties	0.54	-2.43	-1.61	-0.91	-0.29

Table 6. Results of Two-Parameter IRT on Diagnosis-Related Self-Stigma Subscale

Item	Discrimination	Difficulty 1	Difficulty 2	Difficulty 3	Difficulty 4
My diagnosis has made me feel I am a weak person	0.90	-0.81	-0.26	0.13	1.25
I have felt that my diagnosis defines me	0.70	-0.73	-0.06	0.46	1.91
I have felt that my diagnosis means I am a 'damaged' person	0.78	-1.15	-0.67	-0.32	1.00
My diagnosis has made me rethink my identity	0.52	-2.08	-1.17	-0.57	1.47
My diagnosis has made me think I am crazy	0.74	-0.60	0.02	0.50	1.55
I have felt I will always be stuck with my diagnosis	0.66	-1.66	-1.03	-0.55	0.70
My diagnosis has made me more reliant on others	0.47	-1.00	0.09	1.02	3.20

As seen in Table 6 above, all items were within the acceptable range for differentiation between strengths of attitude (labelled as 'Difficulty'). Although the last item is below the recommended level of discrimination, the deviation from the acceptable range is minimal and it was thought to capture an important aspect of self-stigma. See Appendix S for the final 19-item Diagnosis Impact Scale.

3.5.6.5. Results for reliability of other measures.

Reliability analyses were carried out on the five construct validity measures. The Patient Feedback on Consultation Skills Questionnaire (PFC) showed excellent internal consistency with a Cronbach's alpha of .97. The SDS-17 social desirability measure had adequate reliability with a Cronbach's alpha of .72. The SWLS had a very high reliability score, its Cronbach's alpha was .90. Similarly, the CORE-10 showed very good reliability with a Cronbach's alpha of .88. The two PANAS scales were analysed separately, showing high reliability on both, Cronbach's alpha of .92 on the

PA scale and .90 on the NA scale. Coefficient alpha values, item means and standard deviations, and 95% confidence intervals are summarised in Table 7.

Table 7. Reliability of Other Measures

Scale	N (items)	Cronbach's alpha	95% CI lower bound (average)	95% CI upper bound (average)	N	Scale mean (adjusted for no. of items)	Standard Deviation
PFC	16	.97	0.96	0.97	248	2.58	0.86
SDS-17	17	.72	0.66	0.76	245	0.48	0.19
SWLS	5	.90	0.87	0.92	247	3.60	1.52
CORE-10	10	.88	0.86	0.90	249	2.76	0.86
PANAS (PA)	10	.92	0.90	0.93	249	2.54	0.86
PANAS (NA)	10	.90	0.88	0.91	248	2.64	0.87

3.5.6.6. Reliability of the DIS.

Following an exploratory factor analysis, the DIS was deemed to have two separate dimensions: Helpfulness of Diagnosis (12 items) and Diagnosis-Related Self-Stigma (seven items). Both scales were subject to reliability analyses to assess internal consistency across items. There were 256 participants in the reliability analysis of the HoD subscale and 263 in the DRSS subscale analysis. Reliability of the subscales was found to be very high, with Cronbach's alphas of .93 for HoD and .81 for DRSS (Table 8). Confidence intervals ranged from 0.92 to 0.95 and 0.78 to 0.85 for HoD and DRSS subscales respectively. The HoD subscale had a minimum possible score of 12 and a maximum possible score of 60. The mean total score was 35.60 with a standard deviation of 14.29 (Table 9). The DRSS subscale had a minimum possible score of 7 and a maximum possible score of 35. The mean total score of this dimension was 19.56 with a standard deviation of 7.71 (Table 9). The scale means adjusted for number of

items were 2.97 for the HoD subscale and 2.79 for the DRSS, the item mean range was 2.37 to 3.87 for the HoD (Table 10) and 2.55 to 3.59 for the DRSS (Table 11). All items fell within the widely accepted ranges for skewness (-1 to 1) and kurtosis (-2 to 2), showing no evidence of floor or ceiling effects.

Table 8. Reliability of the DIS

Scale	N (items)	Cronbach's alpha	95% CI lower bound (average)	95% CI upper bound (average)	N	Scale mean (adjusted for no. of items)	Standard Deviation
HoD	12	.93	0.92	0.95	256	2.97	1.19
DRSS	7	.81	0.78	0.85	263	2.79	1.10

Table 9. DIS Subscale Means, Medians, Standard Deviations, and Ranges

Scale	N (items)	N	Mean Total	Median	Standard deviation	Range
HoD	12	311	35.60	39.00	14.29	59.00
DRSS	7	311	19.56	20.00	7.71	33.00

Table 10. Helpfulness of Diagnosis Subscale Item Means, Standard Deviations, Skewness and Kurtosis

Item	Mean	Standard Deviation	Skewness	Kurtosis
It would have been better if I had not been diagnosed*	3.87	1.424	-.905	-.637
My diagnosis has led to me being happier	2.76	1.346	.040	-1.258
My diagnosis has been comforting	2.84	1.313	-.120	-1.307
My diagnosis has given me hope	2.75	1.284	.023	-1.153
My diagnosis has made me feel my mental health difficulties are taken seriously	3.41	1.309	-.591	-.814
My diagnosis has helped me to understand myself better	3.68	1.234	-.892	-.080
My diagnosis has made me feel more 'normal'	2.54	1.275	.216	-1.215

My diagnosis has helped me to feel better about myself	2.71	1.326	.060	-1.258
My diagnosis has made my difficulties worse*	2.37	1.328	.596	-.844
My diagnosis has given me greater access to professional help	3.35	1.454	-.497	-1.177
Thanks to my diagnosis I have been more willing to seek professional help	3.52	1.292	-.759	-.504
My diagnosis has motivated me to find better ways of managing my difficulties	3.73	1.222	-.940	-.019

*****Reverse-coded items

Note: Scoring of the scale was on a 5-point Likert scale (1=Strongly disagree, 2=Somewhat agree, 3=Neither agree nor disagree, 4=Somewhat agree, 5=Strongly agree.

Table 11. Diagnosis-Related Self-Stigma Subscale Item Means, Standard Deviations, Skewness, and Kurtosis

Item	Mean	Standard Deviation	Skewness	Kurtosis
My diagnosis has made me feel I am a weak person	2.95	1.461	-.092	-1.447
I have felt that my diagnosis defines me	2.69	1.391	.097	-1.415
I have felt that my diagnosis means I am a 'damaged' person	3.34	1.410	-.538	-1.080
My diagnosis has made me rethink my identity	3.43	1.335	-.613	-.859
My diagnosis has made me think I am crazy	2.65	1.452	.226	-1.402
I have felt I will always be stuck with my diagnosis	3.59	1.385	-.700	-.810
My diagnosis has made me more reliant on others	2.55	1.342	.224	-1.323

3.5.6.7. Construct validity results.

Convergent validity.

As expected, there was a large positive correlation ($r=.69$, $p<.01$) between the HoD subscale and the Patient Feedback on Consultation Skills Questionnaire (PFC). This indicates that participants who experience high diagnosis helpfulness also have

high levels of satisfaction with communication of and about diagnosis, and is a clear indication of convergent validity. There was a medium negative correlation between the DRSS subscale and PFC scores ($r=-.34$, $p<.01$). This suggests that those with high diagnosis-related self-stigma have low communication satisfaction. The difference in correlation size between the two DIS subscales indicates that communication satisfaction is more important for helpfulness of diagnosis than diagnosis-related self-stigma.

As anticipated, there was a small positive correlation between the Satisfaction with Life Scale and the HoD subscale of the DIS ($r=.29$, $p<.01$) and a small negative correlation with the DRSS subscale ($r=-.29$, $p<.01$). This suggests that participants with high HoD scores also report high life satisfaction. Conversely, those with high life satisfaction scores have low DRSS scores.

Also in line with expectations, there was a large positive correlation between the single-item diagnosis helpfulness measure and the HoD subscale ($r=.68$, $p<.01$). The negative correlation between diagnosis helpfulness and the DRSS subscale was small, but still reached significance ($r=-.21$, $p<.01$). These results indicate that those with high diagnosis helpfulness scores have high HoD and low DRSS scores. Cases were excluded listwise, meaning that only participants who responded to all items of both subscales were included in the analysis. See Table 12 below for full convergent validity statistics.

Table 12. Convergent Validity of DIS Subscales

Validity Scale	N	Helpfulness of Diagnosis	Diagnosis-Related Self-Stigma
PFC	254	.69**	-.34**
SWLS	252	.29**	-.29**
Single-Item Measure	304	.68**	-.21**

** Correlation is significant at the .01 level (2-tailed).

Discriminant validity.

There were no significant correlations between the subscales of the DIS (-.01 with HoD and -.05 with DRSS) and the social desirability measure, SDS-17, suggesting that the scale does not attract a social desirability response bias.

There was a small negative correlation ($r=-.24$, $p<.01$) between the HoD subscale of the DIS and the CORE-10 indicating that those with high levels of psychological distress experience low levels of diagnosis helpfulness. There was a medium positive correlation between the DRSS subscale and the CORE-10 ($r=.39$, $p<.01$) indicating that those experiencing high levels of psychological distress also report high levels of diagnosis-related self-stigma.

As expected, there was no significant correlation between the PANAS PA and the HoD subscale ($r=.12$, $p<.01$). There was a small negative correlation between the DRSS subscale and the PANAS PA scale ($r=-.21$, $p<.01$), suggesting that those who report high levels of diagnosis-related self-stigma have low levels of positive affect. There was a medium positive correlation between the PANAS NA scale and the DRSS subscale ($r=.35$, $p<.01$), indicating that those who report high diagnosis-related self-stigma also have high negative affect. There was a small negative correlation between the NA scale and the HoD subscale of the DIS ($r=-.18$, $p<.01$). This shows that participants with high negative affect report low helpfulness of diagnosis. As above, cases were excluded listwise. See Table 13 for full discriminant validity statistics.

Table 13. Discriminant Validity of DIS Dimensions

Validity Scale	N	Helpfulness of Diagnosis	Diagnosis-Related Self-Stigma
SDS-17	252	-.01	-.05
CORE-10	252	-.24**	.39**
PANAS (PA)	251	.12	-.21**

PANAS (NA)	251	-.18**	.35**

** Correlation is significant at the .01 level (2-tailed).

3.5.6.8. Criterion validity results.

Independent-samples t-tests were carried out on dichotomous variables, see Table 14 for full HoD results and Table 15 for full DRSS results. Cases were excluded listwise, meaning that any participant who did not complete all items of both subscales (HoD and DRSS) was removed from the analysis. A bivariate correlation was conducted on the continuous variable, treatment helpfulness, see Table 16 for results. Again, cases were excluded listwise.

In terms of HoD, participants who were receiving treatment (M=37.58, SD=12.85) had higher scores compared to those who were not (M=33.06, SD=15.53); t(302)=2.60, p=.01. Similarly, those who felt their diagnosis was correct (M=40.94, SD=11.48) had significantly higher HoD scores than those who did not (M=21.45, SD=11.50); t(253)=11.16, p=.00. There were no significant differences found for the other dichotomous variables; receipt of formal assistance in employment or education/training, or having multiple diagnoses.

Table 14. Criterion Validity T-Test Results for Helpfulness of Diagnosis Subscale

Variable	Level	N	Mean	Stand. Dev.	Sig.	T	95% CI upper	95% CI lower
Formal assistance in employment/ education/training	Yes	76	39.67	13.71	.69	1.82	6.94	-0.27
	No	169	36.34	13.02				
Receiving treatment due to diagnosis	Yes	192	37.58	12.85	.01*	2.60	7.94	1.10
	No	112	33.06	15.53				
Perceived correct Diagnosis	Yes	200	40.94	11.48	.00**	11.16	22.96	16.07
	No	55	21.45	11.50				
Multiple diagnoses	Yes	190	35.66	14.29	.43	-0.79	1.10	-4.68
	No	108	36.81	13.71				

** Difference is significant at the .01 level (2-tailed). *Difference is significant at the .05 level (2-tailed).

In terms of diagnosis-related self-stigma, participants who were in receipt of treatment due to their diagnosis (M=20.42, SD=7.37) had significantly higher scores than those who were not (M=18.44, SD=7.79); t(302)=2.21, p=.03. Those who perceived their diagnosis to be correct (M=18.76, SD=7.21) scored significantly lower on the DRSS subscale than those who did not (M=21.78, SD=8.86); t(253)=-2.33, p=.02. Finally, DRSS scores were significantly higher among participants who had multiple diagnoses (M=20.55, SD=7.53) than those who did not (M=18.31, SD=7.48); t(296)=2.47, p=.01. There were no significant differences found between groups for receipt of formal assistance in employment or education/training.

Table 15. Criterion Validity T-Test Results for Diagnosis-Related Self-Stigma Subscale

Variable	Level	N	Mean	SD	Sig.	T	95% CI upper	95% CI lower
Formal assistance in employment/ education/ training	Yes	76	19.66	7.30	.38	0.81	2.91	-1.12
	No	169	18.73	7.45				
Receiving treatment due to diagnosis	Yes	192	20.42	7.37	.03*	2.12	3.74	0.22
	No	112	18.44	7.79				
Perceived correct Diagnosis	Yes	200	18.76	7.21	.02*	2.33	-0.43	-5.61
	No	55	21.78	8.86				
Multiple diagnoses	Yes	190	20.55	7.53	.01*	2.47	4.02	0.46
	No	108	18.31	7.48				

*Difference is significant at the .05 level (2-tailedd).

As data for some variables was not normally distributed, Spearman's correlations were used. As seen in Table 16 below, there was a large correlation between HoD and treatment helpfulness (rho=.52) suggesting that those receiving helpful treatment due to their diagnosis also experience greater helpfulness of diagnosis.

There was a moderate negative correlation between DRSS and treatment helpfulness (rho=-.34). This indicates that those who were receiving helpful treatment due to their diagnosis experienced lower levels of diagnosis-related self-stigma.

Table 16. Spearman Correlation between Treatment Helpfulness and DIS Dimensions

Variable	N	Helpfulness of Diagnosis	Diagnosis-Related Self-Stigma
Treatment helpfulness	186	.52**	-.34**

**. Correlation is significant at the .01 level (2-tailed). *Correlation is significant at the .05 level (2-tailed).

Type of diagnosis.

There was a broad variety of diagnoses within the sample. Although participants were asked to specify one diagnosis (if they had received more than one, they were asked to give the diagnosis that held most importance for them), some listed multiple. These individuals were not included in the analysis of diagnosis type as it was not possible to deduce which might be the most salient diagnosis. This left 47 specific disorders which were categorised, see Table 17 below for simplified categories. A one-way ANOVA was carried out to compare HoD and DRSS scores of participants based on their diagnosis type. There was a significant difference between HoD scores by diagnosis type, $F(6, 271)=4.84$, $p<.05$. DRSS scores were also significantly different across diagnosis type, $F(6, 271)=3.82$, $p=.001$.

Table 17. Descriptive Statistics for Type of Diagnosis

	Helpfulness of Diagnosis			Diagnosis-Related Self-Stigma		
	n	Mean	Standard deviation	n	Mean	Standard deviation
Depressive disorder	94	34.83	12.58	94	18.24	8.01
Anxiety disorder	62	40.47	8.56	62	17.56	5.92
Personality disorder	44	30.09	12.97	44	23.09	6.99
Bipolar disorder	27	33.11	14.85	27	20.67	7.10
	18	35.67	8.98	18	20.44	8.15

Mixed anxiety and depressive disorder	15	34.27	11.95	15	20.87	7.92
Eating disorder	18	27.11	13.11	18	22.78	7.02
Other						

Bonferroni post hoc tests on the HoD subscale showed that those who had anxiety disorder diagnoses (M=40.47, SD=8.56) had significantly higher scores than those with personality disorder diagnoses (M=30.09, SD=12.97; p=.000). Those who had anxiety disorder diagnoses (M=40.47, SD=8.56) also had significantly higher HoD scores than those within the 'Other' diagnosis category (M=27.11, SD=13.11; p=.001).

DRSS scores of participants with personality disorder diagnoses (M=23.09, SD=6.99) were significantly higher than those with anxiety disorder diagnoses (M=17.56, SD=5.92; p=.003). DRSS scores of those with personality disorder diagnoses (M=23.09, SD=6.99) were also significantly higher than those with depressive disorder diagnoses (M=18.24, SD=8.01; p=.007).

3.5.6.9. Socio-demographic variable association results.

Although three gender options were given in the online survey ('Male', 'Female', and 'Other'), the sample size for 'Other' was too small for meaningful analysis (n=6), therefore gender was analysed as a dichotomous variable. No significant differences were found on either dimension of the DIS. No significant difference was found between HoD or DRSS scores based on mental health professional status. See Table 18 below for full details. There were no significant differences in DRSS scores based on gender or mental health professional status (Table 19).

Table 18. Socio-Demographic Variable T-test Results for Helpfulness of Diagnosis Subscale

Variable	Level	N	Mean	Stand. Dev.	Sig.	T	95% CI upper	95% CI lower

Gender	Male Female	53 249	34.81 36.36	13.16 14.18	.47	-0.73	5.72	2.62
Mental health professional	Yes No	78 228	36.04 35.77	14.11 14.02	.88	0.15	3.90	-3.35

Table 19. Socio-Demographic Variable T-test Results for Diagnosis-Related Self-Stigma Subscale

Variable	Level	N	Mean	SD	Sig.	T	95% CI upper	95% CI Lower
Gender	Male Female	53 249	18.25 19.88	6.91 7.65	.15	-1.44	-3.88	0.61
Mental health Professional	Yes No	78 228	18.82 20.05	7.46 7.61	.22	-1.24	0.72	-3.19

There was a small negative correlation between the HoD subscale and age (r=-.15, p<.05). This suggests that the helpfulness of the diagnosis decreases with increasing age. There was no significant correlation found between age and DRSS(r=-.03). See Table 20 for results of Pearson correlations.

Table 20. Pearson Correlations between Socio-Demographic Variables and DIS Dimensions

Variable	N	Helpfulness of Diagnosis	Diagnosis-Related Self-Stigma
Age	308	-.15*	-.03

**. Correlation is significant at the .01 level (2-tailed). *Correlation is significant at the .05 level (2-tailed).

There was a small negative correlation between HoD and time since diagnosis (rho= -.12). This suggests that diagnosis helpfulness decreases as time passes. As mentioned above, there was also a significant negative correlation between age and HoD.

A partial correlation was conducted, controlling for time since diagnosis, to assess whether the correlations seen with age were due to the time since diagnosis. This showed no correlation between age and HoD (r=-.09) or DRSS (r=-.08). In addition, when age was controlled for, there was no significant correlation between time since diagnosis and HoD (r=-0.09) or DRSS (r=0.09). This suggests that age and time since diagnosis are overlapping variables.

There was no significant correlation between HoD and the number of diagnoses received (rho=-.13). There was a small correlation between DRSS and number of diagnoses received (rho=.15). This suggests that diagnosis-related self-stigma increases with higher numbers of diagnoses. There was no significant correlation between time since diagnosis and DRSS (rho=.03). See Table 21 for full details.

Table 21. Spearman Correlations between Socio-Demographic Variables and DIS Dimensions

Variable	N	Helpfulness of Diagnosis	Diagnosis-Related Self-Stigma
Time since diagnosis	301	-.12*	.03
Number of diagnoses	175	-.13	.15*

**Correlation is significant at the .01 level (2-tailed). *Correlation is significant at the .05 level (2-tailed)

Diagnosing professional.

A large majority of participants received their diagnosis from a psychiatrist (n=139) or general practitioner (n=112), see Table 22 for full details. A one-way ANOVA was conducted to compare both HoD and DRSS scores by diagnosing professional. The result for HoD was non-significant, F(5, 299)=0.58, p=.72. Bonferroni and LSD post hoc tests were also non-significant.

Table 22. Diagnosing Professional Descriptive Statistics

	Helpfulness of Diagnosis			Diagnosis-Related Self-Stigma		
	n	Mean	Standard deviation	N	Mean	Standard deviation
Psychiatrist	139	34.81	15.21	139	20.75	7.65
General practitioner (GP)	112	37.54	11.94	112	17.76	7.40
Psychologist	18	35.39	16.45	18	20.17	7.30
Psychotherapist	12	36.08	13.07	12	22.92	4.81
Counsellor	10	37.80	14.51	10	20.10	6.71
Other	14	33.71	15.49	14	22.36	8.33

When DRSS scores were compared according to diagnosing professional there was a significant ANOVA result, $F(5, 299)=2.89$, $p=.02$. Bonferroni post hoc tests showed that participants who received their diagnosis from a psychiatrist had significantly higher DRSS scores ($M=20.75$, $SD=7.65$) than those who received their diagnosis from a general practitioner ($M=17.76$, $SD=7.40$; $p=.03$).

Ethnicity.

Participant numbers in non-white categories were too small to allow for meaningful comparison of diagnosis impact across ethnicities.

Chapter 4:
Discussion

4.1. Two Dimensions of Diagnosis Impact: Helpfulness of Diagnosis and Diagnosis-Related Self-Stigma

The two-factor model of diagnosis impact reflects the overall pattern in existing research which indicates that diagnoses can be helpful on an emotional level and have practical benefits, but they often attract stigma which is often internalised and experienced as unhelpful. This suggests that diagnosis impact is bi-dimensional and more complicated than finding a diagnosis either helpful or unhelpful.

The content of the HoD and DRSS subscales reflects the most prominent themes in existing research. Service-users report the significant emotional impact of diagnosis (Abbot et al., 2012; Cleradin, 2012; Moeke-Maxwell et al., 2008; Perkins et al., 2018; Vernooij Dassen et al., 2006) and that diagnoses are most helpful if they have functional value and conversely unhelpful if this is lacking (Perkins et al., 2018), and the most frequently cited negative outcome of receiving a mental health diagnosis cited in the literature is stigma (Link & Phelan, 2013; Manderscheid et al., 2010). As the social impact subscale was excluded from the psychometric analysis, due to the large number of participants who did not respond to these items and high level of 'Not applicable' responses across the items, social or public stigma was not measured. However, the second factor, Diagnosis-Related Self-Stigma, is thought to represent the recipient's internalisation of public perceptions of people with mental health difficulties.

4.1.1. Helpfulness of Diagnosis.

The Helpfulness of Diagnosis dimension of the DIS is made up of 12 items. Nine of these relate to the emotional value of the diagnosis, such as: 'It would have been better if I had not been diagnosed', 'My diagnosis has led to me being happier',

‘My diagnosis has been comforting’, and ‘My diagnosis has made me feel more ‘normal’’. The three remaining items address the more practical benefits of the diagnosis in managing mental health difficulties or accessing treatment, these are: ‘My diagnosis has given me greater access to professional help’, ‘Thanks to my diagnosis I have been more willing to seek professional help’, and ‘My diagnosis has motivated me to find better ways of managing my difficulties’.

4.1.2. Diagnosis-Related Self-Stigma.

The Diagnosis-Related Self-Stigma dimension of the DIS is made up of seven items which relate to the internalisation of stigma and negative impact on identity. These items are ‘My diagnosis has made me feel I am a weak person’, ‘I have felt that my diagnosis defines me’, ‘I have felt that my diagnosis means I am a 'damaged' person’, ‘My diagnosis has made me rethink my identity’, ‘My diagnosis has made me think I am crazy’, ‘I have felt I will always be stuck with my diagnosis’, and ‘My diagnosis has made me more reliant on others’. The content of these items indicates that the DRSS dimension of the DIS aligns with existing theory on self-stigma.

Self-stigma is a subcategory of stigma (Pescosolido & Martin, 2015). It is defined as a four stage process in which an individual who is part of a stigmatized group and conscious of the stigma attached to this group, endorses the publicly held negative beliefs about the group, associates these prejudices with the self, and suffers adverse consequences of this internalisation (Corrigan & Rao, 2012). It is therefore a culturally-bound and dependent experience as the negative self-view is directly informed by societal perceptions of stigmatized groups (Corrigan et al., 2018; Livingston & Boyd, 2010). Research indicates that self-stigma due to mental health difficulties has an extremely negative impact on those who experience it, including a sense of shame, culpability, and inferiority to those who do not experience mental health difficulties

(Dinos, Stevens, Serfaty, Weich, & King, 2004; Stevelink, Wu, Voorend, & van Brakel, 2012). Other consequences of this type of self-stigma are reduced social functioning, social withdrawal, diminished quality of life, lack of mental and physical health and wellbeing, and suicidal ideation (Camp, Finlay, & Lyons, 2002; Link, Struening, Neese-Todd, Asmussen, & Phelan, 2001; Livingston & Boyd, 2010; Mak, Poon, Pun, & Cheung, 2007; Rusch, Zlati, Black, & Thornicroft, 2014; Wahl, 1999). There is also an association between mental health-related self-stigma and poor treatment engagement (Corrigan et al., 2009).

4.2. Reliability and Validity

4.2.1. Content validity.

The pre-psychometric exploration version of the DIS showed good content and face validity. Items were selected based on item rating and Three-Step Test Interviews with diagnosis recipients. Results of these stages indicated that the items of the DIS were relevant and important to the construct of diagnosis impact.

4.2.2. Dimensionality.

Two separate factors were indicated by the exploratory factor analysis; Helpfulness of Diagnosis and Diagnosis-Related Self-Stigma. These factors accounted for a good proportion of the variance at 53.60% (Field, 2018). The first factor, Helpfulness of Diagnosis, was strong, accounting for 42.49% of the variance and the second factor represented a further 11. 11%. There was a small negative correlation between the factors (r=-.24) indicating two distinct dimensions of diagnosis impact. There have been no previous scale development studies on the impact of psychiatric diagnosis on recipients, so the dimensionality of the scale could not be compared with existing measures. However, as mentioned above in Two Dimensions of Diagnosis

Impact: Helpfulness of Diagnosis and Diagnosis-Related Self-Stigma, the two-dimensional model and its subscale constructs reflect the most salient aspects of diagnosis impact reported by previous studies.

4.2.3. Reliability.

Both subscales of the DIS had high coefficient alpha values and all items contributed to the reliability of their respective subscales. This indicates very good internal consistency of the HoD and the DRSS.

4.2.4. Construct validity.

The DIS displayed good construct validity which was assessed using convergent and discriminant validity measures.

4.2.4.1. Convergent validity.

The DIS showed very good convergent validity with the Patient Feedback on Consultation Skills Questionnaire (PFC) with a large positive correlation with HoD and a medium negative correlation with DRSS. Both correlations are as expected and in line with previous research (Laird et al., 2009; Pitt et al., 2009). The positive correlation with HoD supports Laird et al.'s (2009) findings which suggest that satisfaction with communication of and about a diagnosis can contribute to a positive experience of the diagnosis itself. The negative correlation with DRSS is in line with Pitt et al.'s (2009) finding that dissatisfaction with communication is associated with a sense of being adversely labelled. Although the findings of the current research are generally similar to those of previous studies in terms of direction of correlations, it is important to note that the DIS dimensions do not map precisely onto themes reported in previous research above i.e. helpfulness is likely to be an aspect of positive experience of diagnosis rather than being synonymous with it and feeling adversely labelled does not necessarily result in an internalisation of this.

The DIS showed good convergent validity with the Satisfaction with Life Scale (SWLS) with a medium positive correlation with HoD and a medium negative correlation with DRSS. The direction of these correlations is as expected. The correlation with both subscales suggests that some of the variance in diagnosis impact scores may be due to life satisfaction. This association between the SWLS and dimensions of the DIS may also be partly due to the scale type as they are both satisfaction scales. The somewhat modest size of the correlations reflects divergence in the scope of the constructs being measured, diagnosis impact is very specific in comparison to the broad nature of overall life satisfaction.

As anticipated, the HoD subscale of the DIS correlated very highly with the single-item diagnosis helpfulness item while there was a small yet significant negative correlation with self-stigma. This indicates, unsurprisingly, that HoD and diagnosis helpfulness are similar constructs, showing clear convergent validity of the HoD subscale. The large correlation reflects their similarity in terms of practical nature of both constructs. The small correlation between DRSS and diagnosis helpfulness indicates that the relationship between these is quite weak. This is not surprising as one would expect that those who have high levels of self-stigma due to their diagnosis would have low diagnosis helpfulness scores. Additionally, the self-stigma scale consists entirely of emotionally-charged items on the internalisation of stigma while diagnosis helpfulness is broader and less emotionally valenced.

4.2.4.2. Discriminant validity

In line with expectations, there was no correlation between the DIS subscales and the SDS-17, indicating a lack of social desirability response bias.

Findings for the CORE-10 and the PANAS were mixed, with some moderate and small correlations found. Initially, when the scale was being developed, small or

non-significant correlations were anticipated with the CORE-10 and PANAS as the impact of diagnosis was considered to be a different construct to psychological distress and positive or negative affect. However, it was acknowledged that there may be some interaction and given the subscales which emerged from the psychometric exploration, and the large number of emotionally-charged items therein, slightly larger correlations were expected. As all psychometric data was collected simultaneously, it was not possible to select validity measures based on the precise dimensions of diagnosis impact.

The small correlation between the CORE-10 and the HoD subscale suggests a slight link between helpfulness of diagnosis and psychological distress. It is possible that the emotional aspect of the HoD subscale contributed to this. The moderate correlation between the DRSS subscale and the CORE-10 indicates a stronger association between psychological distress and diagnosis-related self-stigma. It is also possible that the highly affective nature of both scales contributed to the size of this correlation. The smaller correlation with the more practical HoD subscale supports this theory.

The small correlation between the DRSS subscale and the PANAS PA suggests an association between emotionality and diagnosis impact scores. However, as above, the emotional valency of both scales may account for this. The medium correlation between DRSS and the PANAS NA suggests that DRSS scores may be contaminated by negative affect and again, the size of this correlation may be partly reflective of both scales being emotionally valenced. As expected, no significant correlation was found between the HoD subscale and the PANAS PA. The small correlation between HoD and the PANAS NA indicates a slight association between overall affect and helpfulness of diagnosis and a potential contribution of the emotional aspect of the HoD subscale to

this relationship. The lack of a strong relationship with the more practical HoD subscale supports the theory that the association between the PANAS and DRSS is due to the highly affective nature of the latter rather than suggesting that diagnosis impact and inherent emotionality are similar constructs.

As detailed previously, the DRSS subscale showed higher correlations with two of the discriminant validity measures (CORE-10 and PANAS NA) than with convergent validity measures. Although this is believed to be partly due to the specificity of the DRSS subscale and its emotional valency, because of their size, the correlations with the CORE-10 and PANAS NA are not considered to support the discriminant validity of the self-stigma subscale. These results do not align fully with some of the original expectations regarding validity, however, they are not surprising given the DIS dimensions that emerged from the factor analysis. Additionally, the other results provide sufficient evidence for the discriminant validity of the scale.

4.2.5. Criterion validity.

4.2.5.1. Diagnosis type.

A significant difference was found between HoD scores of participants with different psychiatric diagnosis types. There was also a significant difference between DRSS scores of those with different diagnosis types. Post hoc tests showed that those with anxiety disorder diagnoses had significantly higher HoD scores than those with personality disorder diagnoses. Also, those with personality disorder diagnoses had significantly higher DRSS scores than those with anxiety or depressive disorder diagnoses.

The findings on helpfulness of diagnosis are as anticipated and in keeping with previous research. Perkins et al. (2018) found that personality disorder diagnoses were more commonly associated with poor communication from services and non-disclosure

of diagnosis than other diagnoses. In addition, they were most associated with withdrawal of care and considered to have the least practical benefits of disorders analysed.

The diagnosis-related self-stigma results are also in line with expectations based on existing research. Perkins et al. (2018) found that personality disorder diagnoses had a greater adverse effect on identity and optimism than other diagnoses. They were also more likely to be linked to discrimination from mental health services and social stigma. Grambal et al. (2016) found that participants diagnosed with borderline personality disorder had significantly higher self-stigma scores than those with psychotic, depressive, and anxiety disorders. The current study did not yield a specific result for borderline personality disorder as personality disorder diagnoses were grouped together for analysis. Also, some participants did not specify which personality disorder diagnosis they received. Nevertheless, the current findings are congruent with those of Grambal et al. (2016). The anticipated findings for the HoD and DRSS subscales support the criterion validity of the DIS as they are in line with previous research which suggests that personality disorder diagnoses are experienced as less helpful compared to other diagnoses. It was expected that participants with a diagnosis of schizophrenia would show similar results, however, there was an insufficient number of participants with this diagnosis (n=3) for meaningful analysis. Further research is required to compare the impact of a schizophrenia diagnosis with that of other diagnoses.

4.2.5.2. Perceived correct diagnosis.

As anticipated, HoD scores of those who believed they had received the correct diagnosis were significantly higher than those who did not hold this belief. Also as expected, DRSS scores of those who believed their diagnosis was correct were significantly lower than those who did not. This is congruent with previous research

which suggests that diagnosis fit may be associated with a positive attitude toward one's psychiatric diagnosis.

Research suggests that diagnoses that fit recipients' experiences are more likely to be reported as helpful (Perkins et al., 2018; Rose & Thornicroft, 2010). Conversely, diagnoses that were seen by the recipient as a poor fit, incorrect, or inadequate, were deemed unhelpful (Bilderbeck et al., 2014; Highet et al., 2009; Horn et al., 2007; Laird et al., 2009). HoD and DRSS subscale results therefore supported previous findings, that feeling one has received the correct diagnosis is linked to it being experienced more positively. These results show clear evidence of criterion validity of the DIS.

4.2.5.3. Multiple diagnoses.

Consistent with previous findings, the majority of participants (61.59%) had received more than one diagnosis (Milton & Mullan, 2015; Moeke-Maxwell et al., 2008; Thomas et al., 2013). However, it is possible that this study, with its focus on diagnosis, appealed to people with significant experience with diagnosis which may come from receiving more than one diagnostic label. There was no significant difference in HoD scores between those who had received a single diagnosis and those who had received multiple diagnoses. Findings of previous research on multiple or changing diagnoses are mixed (Milton & Mullan, 2015; Moeke-Maxwell et al., 2008), therefore there was no firm a priori hypothesis on diagnosis helpfulness. The lack of a significant difference in HoD scores between those who had single versus multiple diagnoses contradicts some previous research. In terms of diagnosis helpfulness, one study suggests that changes to diagnoses can be disruptive and confusing for service users (Moeke-Maxwell et al., 2008). Milton and Mullan (2015) found a potential interaction between diagnosis fit and the effect of multiple diagnoses on diagnosis impact, as participants found changes helpful if they resulted in better diagnosis fit. The

interaction was not investigated in this study, therefore results cannot be easily compared.

A significant difference was found between DRSS scores of participants who received a single diagnosis and those who received multiple. Again because of the mixed results reported in existing studies relating to multiple diagnoses, hypotheses on self-stigma and multiple diagnoses were quite speculative.

The DRSS findings are in line with previous research that indicates high levels of perceived diagnosis-related public stigma (Hamilton et al., 2014; Howe et al., 2014; Laird et al., 2009; Link, 1987; Moeke-Maxwell et al., 2008; Thomas et al., 2013; Uhlmann et al., 2014) which could logically be expected to be compounded by additional diagnoses. Therefore, the diagnosis-related self-stigma findings are somewhat indicative of criterion validity but this was a tentative enquiry due to the lack of a clear hypothesis based on previous research.

4.2.5.4. Receipt of treatment due to diagnosis.

Those who were in receipt of treatment due to their diagnosis had significantly higher HoD scores than those who were not. This supports results of previous research which indicate that when a diagnosis has a functional value, it is more likely to be experienced as helpful (Perkins et al., 2018). Somewhat contrary to expectations, those receiving treatment due to their diagnosis also had higher DRSS scores. This finding is in contrast with the results of Perkins et al.'s (2018) large-scale meta-analysis. They found that service users felt more positive about their diagnosis if it led to appropriate treatment. In addition, service users expected to receive treatment following diagnosis and were shocked if this was not the case. The diagnosis helpfulness results in this study support the findings above, with those in receipt of treatment reporting greater diagnosis as more helpful than those who were not. However, the high DRSS scores in those

receiving treatment somewhat contradict Perkins et al. (2018)'s findings. However, it is possible that those in receipt of treatment due to their diagnosis experience more severe mental health difficulties or have a more highly stigmatised diagnosis types. Further research is necessary to investigate this interaction.

It is also possible that if someone is receiving treatment which is recommended by healthcare professionals, there is an implication that it is necessary, which may be interpreted as indicative of a certain level of pathology or severity of mental health difficulties. This could contribute to the internalisation of diagnosis-related stigma and an individual's sense that there is something 'wrong' with them. However, it is not clear from the data collected whether the treatment being received was directly recommended by a healthcare professional, although this is implied by the item, 'Are you currently receiving treatment because of your diagnosis?', it is possible that some participants selected their treatment independently. The current findings lend some support to the criterion validity of the DIS.

4.2.5.5. Treatment helpfulness.

Participants who reported receiving treatment due to their diagnosis were asked how helpful said treatment was. There was a large correlation between treatment helpfulness and HoD subscale scores and a moderate negative correlation with DRSS scores. These results are as anticipated and as they are consonant with those of Perkins et al. (2018) described above, clearly support the hypothesis that the DIS shows criterion validity.

4.2.5.6. Formal assistance in employment/education/training.

There was no significant difference found between those in receipt of formal assistance in employment or education/training and those who were not. It was expected that those receiving assistance would have higher scores on the HoD subscale based on

Perkins et al.'s (2018) finding that when diagnosis results in practical benefits it is experienced more positively. However, it is likely that those who were receiving formal assistance in their job or educational setting due to their diagnosis also experienced greater functional impairment caused by their mental health difficulties. This may explain the similar HoD scores across those in receipt of formal assistance and those who were not. Lower scores on the DRSS subscale were expected for participants receiving formal assistance based on the same previous research finding. However, these hypotheses were tentative as no previous research examined the relationship between diagnosis impact and formal assistance in employment/education/training per se. Research suggests that disclosure of diagnosis in occupational settings can lead to stigma (Corrigan, 2004; Mendel et al., 2013; Rusch, Angermeyer, & Corrigan, 2005). It is possible that the disclosure leading to formal assistance resulted in stigma which was in turn internalised by participants.

4.3. Associations with Demographic Variables

4.3.1. Gender.

The higher self-stigma scores in the 'Other' gender category may suggest intersectionality issues whereby psychiatric diagnosis is linked to greater internalisation of stigma in these recipients than those who identify as males and females. Conclusions cannot be drawn based on this small sample and further research is warranted to investigate this relationship.

4.3.2. Age.

The small negative correlation between HoD and age indicates that older participants experience their diagnosis as less helpful. However, further research is required to investigate whether this is due to age at receipt of diagnosis or increasing age.

There is no coverage of the relationship between age and experience of psychiatric diagnosis in the existing research, therefore there were no a priori hypotheses. There was no correlation between age and DRSS suggesting that self-stigma due to diagnosis is stable as age increases. Further research is required to investigate diagnosis-related self-stigma levels in middle aged and older adults as the majority of participants (62.74%) were under 40 years of age.

4.3.3. Number of diagnoses.

There was no significant correlation between the number of diagnoses and the HoD subscale and a small correlation with DRSS subscale. No exiting studies investigated the relationship between precise number of diagnoses and diagnosis impact. Therefore, there were no a priori hypotheses on the relationship between this variable and DIS scores. It was included for exploratory purposes.

4.3.4. Time since diagnosis.

The small negative correlation between HoD and time since diagnosis is in keeping with some existing research which found an increasingly negative attitude to diagnosis over time when expectations were not realised (Cleradin, 2012; Moeke-Maxwell et al., 2008). However, there were no a priori assumptions about the relationship with time since diagnosis due to the mixed nature of previous research. Also, existing research investigated the effect of time during the initial post-diagnostic period while the current study was not time-limited or specific which meant that comparisons could be made between participants who were recently diagnosed and those who had their diagnoses for many years.

The lack of a significant difference in DRSS scores based on diagnosis over time suggests that self-stigma scores do not lessen over time after diagnosis as one might intuitively expect. This result supports Bilderbeck et al.'s (2014) finding that attitudes to

diagnosis remained the same between the initial research interview and the 6-month follow up stage with a sample of participants with ‘mood instability’. However, as mentioned above, findings on the relationship between time and diagnosis impact are mixed. Vernooij-Dassen et al. (2006) reported some practical developments and differences in emotional impact between two and 12 weeks post-diagnosis in participants with dementia and their families, however, there is no clear positive or negative majority in the results. Delmas et al. (2011) found that participants needed time to accept their diagnosis of bipolar disorder which may indicate a positive effect of the passing of time on diagnosis impact in the initial post-diagnostic phase. However, as the results of most previous research are diagnosis-specific, there may be diagnosis-specific differences.

Partial correlations controlling for age showed no significant correlation for either HoD or DRSS and time since diagnosis. This was also true of age when time since diagnosis was controlled for. This finding is understandable as these two variables are intrinsically linked, it is not possible for age to increase without time since diagnosis increasing and vice versa.

4.3.5. Diagnosing professional.

The item on diagnosing professional was included to gather demographic information about participants and as well as providing an additional eligibility check. There was no significant difference between HoD scores based on diagnosing professional. However, there was a significant difference between DRSS scores by diagnosing professional type. Post hoc tests showed that those who were diagnosed by a psychiatrist had significantly higher DRSS scores than those who received their diagnosis from a general practitioner. There were no a priori assumptions about the relationship between diagnosing professional as it was not covered in previous literature

on diagnosis impact. The effect of diagnosing professional on diagnosis-related self-stigma requires further investigation as it may be related to severity of symptoms or disorder type. It is possible that individuals with less severe symptoms are diagnosed by their GP while those with more complex or severe difficulties are referred or initially treated by psychiatrists.

4.3.6. Mental health professional status.

No significant differences were found between mental health professionals and 'lay' participants. There was no a priori expectation of the interaction between mental health professional status and diagnosis impact as the relationship with occupation was not covered in previous research.

4.4. Limitations

The study has some limitations which may influence the interpretation of the results. There are also limitations inherent in the format of the scale and the analysis conducted.

4.4.1. Study limitations.

There are limitations of this study as regards design and the information which can be gathered using the scale. One of the main limitations is the difficulty in isolating the impact of diagnosis on a person's life as distinct from the impact of mental health difficulties and treatment. These different layers of experience are inherently inter-related. Although the scale introduction explicitly states that participants should respond about the effect of their diagnosis specifically, and each item includes the word 'diagnosis', it is possible that some responses may be based more on experience of mental health condition or treatment rather than being diagnosis-specific. This is due to the highly related nature of the phenomena.

Another principal limitation of this study was the lack of comparable measures which could be used to assess construct validity. This is a function of developing a measure of a construct which has not previously been measured. However, the DIS showed acceptable construct validity despite the broad nature of validity measures used. In future analyses, it may be helpful to compare the individual subscales with more specific measures such as self-stigma and self-esteem scales.

As the psychometric exploration was anonymous and conducted online, it is not possible to verify whether participants had diagnoses. However, there was no incentive for individuals to participate if they had not received a diagnosis as there was no payment or reward for participation nor was there undue pressure put on participants to take part.

The study required individuals to self-select. This may have attracted an effect of more extreme experience of or attitude to diagnosis. It is possible that this type of study appeals to people who have had a particularly positive or particularly negative experience of diagnosis rather than being representative of more moderate attitudes. In addition, self-selection may have meant that those who took part were particularly interested in the concept of diagnosis and its effects or been diagnosis recipients who are involved in political or organisational activity relating to diagnosis. It is possible that such participants may differ in their experience of diagnosis from the general population of individuals with psychiatric diagnoses.

The majority of participants were white females under the age of 40 therefore results may be less applicable to other diagnosis recipients. However, there was a reasonable number of males (n=55).

Unfortunately, despite efforts to recruit a sample which was ethnically representative of the population of people with mental health diagnoses, there were

insufficient participant numbers in non-white ethnicity categories to allow for meaningful analysis. As a result, validity of the DIS of across non-white ethnic groups cannot be assumed and further research comparing diagnosis impact across ethnicities is required.

Middle aged and older diagnosis recipients were also under-represented. However, the Adult Psychiatric Morbidity Survey 2014 indicates mental disorder prevalence rates decrease significantly after the age of 64, with prevalence among individuals aged 75 and over being less than half that of those aged 55 to 64 (Stansfeld et al., 2016).

Although the study was posted and advertised online, many of the individuals and organisations who disseminated participant recruitment materials were based in the UK. As a result, the majority of participants were UK residents. This means that further research is required to determine the applicability of results in different countries and across varied cultures. For example, Cheung et al.(2018) suggest that public stigmatisation of schizophrenia may be particularly prevalent in China due to the collectivist culture and high level of interdependence between individuals. This may in turn result in higher DRSS scores in a Chinese context.

4.4.2. Limitations of the scale format.

The introduction to the DIS asked participants to respond to items based on how they experienced their diagnoses since they received them. Due to this broad time frame, results cannot be attributed to any particular period and may be seen as less precise as participants may have had varied experience of their diagnoses over time. However, the removal of the time frame following the TSTI is thought to increase the validity of the scale as it eliminates the possibility that a time frame may be forgotten by

participants and increases the likelihood that items are completed in a more uniform manner.

It could be argued that the self-report nature of the DIS is a limitation. However, as the scale is designed to gather information on the experience of service-users rather than on particular events or points in time this is not considered to be a significant issue. Moreover, the majority of items on both subscales, save for one item on the HoD subscale ('My diagnosis has given me greater access to professional help') pertain to internal experience rather than external 'truths'. From a critical realist perspective, access to the real is inevitably influenced and limited by perception therefore self-report is an explicit manifestation of this.

4.4.3. Limitations in analyses.

The dimensionality of the DIS reported in this thesis is based exclusively on inductive methods of analysis as it does not include a confirmatory factor analysis (CFA). This is required to verify the bi-dimensionality of diagnosis impact as well as the relationship between the subscales. The analysis will be conducted with a separate sample in the coming months, however, it remains a limitation of the results described in this thesis.

As the current study is critical realist rather than positivist, bias is not viewed as a limitation per se but rather an inherent tenet of any research activity. Given the epistemology of the study, researcher influence is not considered to be detrimental to the research process or the integrity of the scale but is of note nevertheless and should be considered in the interpretation of scale output. Although conventions of scale development and factor analysis were adhered to, factor analysis is particularly reliant on the judgements of the researcher. The researcher decided on the number of factors to select and the items which would be excluded from the Helpfulness of Diagnosis

subscale which initially had too many item loadings. Therefore, the DIS is a product not only of statistical analysis but of subjective decision-making.

4.5. Further Research

4.5.1. Further psychometric testing of the DIS.

The results of the psychometric exploration study have indicated some areas which require further study. A confirmatory factor analysis must be conducted to test the two-factor structure of the DIS indicated by the exploratory factor analysis. In order to further validate the DIS, scales which relate more specifically to the DIS subscales will be used e.g. the Internalised Stigma of Mental Illness Inventory (Hammer & Toland, 2017). Participant recruitment will be carried out through a data collection website called Prolific, meaning that subscribed individuals meeting specific criteria can be invited to participate. It is expected that this will increase the likelihood of securing a more ethnically representative sample.

The impact of a schizophrenia diagnosis could not be compared to that of other diagnoses in the current study due to insufficient participants. Therefore, further research is required to establish the validity of the DIS for individuals with a diagnosis of schizophrenia. Findings of previous studies suggest that recipients of this diagnosis report higher levels of unhelpfulness and stigma than participants with other disorder labels (Angermeyer, Beck, Dietrich, & Holzinger, 2004; Crisp, 2004; Ellison, Mason, & Scior, 2013). This indicates that a schizophrenia diagnosis may be found to be associated with low helpfulness of diagnosis and high self-stigma due to diagnosis. Indeed, as diagnosis type has been shown to be salient in this and previous studies, there is a possibility that other disorder categories (in addition to personality disorders and schizophrenia) are also experienced as particularly unhelpful. More targeted research on

this is indicated, ideally comparing large samples of participants from each disorder category of the DSM or ICD.

As the majority of participants (62.74%) were under 40 years of age, it may be helpful to conduct a study with middle aged and older adults in order to establish validity for the DIS across all age categories.

There was a very small number of participants in the 'Other' gender category, meaning that the validity of the DIS for this group is not yet established. Participants in the 'Other' gender category had much higher self-stigma scores than males and females. This finding further emphasises the need for a study on the impact of diagnosis on transgender, gender fluid and non-binary individuals.

4.5.2. Research applications of the DIS.

As high levels of diagnosis-related self-stigma were found in those receiving treatment, the DIS could be used in further quantitative research to investigate the relationship between treatment type and diagnosis impact. One possible approach would involve recruiting participants in receipt of various types of psychological therapies (e.g. humanistic, psychodynamic, cognitive behavioural, systemic) which could allow comparison between self-stigma scores across different modalities. It may also be helpful to compare different combinations of medical and non-medical treatments e.g. therapy alone, therapy and medication, medication without therapy, as well as investigating the effects of duration of therapy and quality of the service-user-clinician relationship. It would be expected that psychological therapies would address self-stigma related to diagnosis if it was a prominent issue for the client. Conversely, exclusively pharmacological treatment without psychological support may increase self-stigma by implying severity of dysfunction without the opportunity to process this.

The current study relates to those who received a diagnosis from a healthcare professional, however, it does not specify the formality of the diagnosis. It may be helpful to examine the relationship between formality of diagnosis and its impact as this may vary depending on whether the diagnosis is a specific DSM or ICD label, written or verbally delivered etc. The current study found a significant difference between those who received their diagnosis from a GPs and psychiatrists. It is possible that the formality of diagnosis differs between professionals and settings depending on conventions and protocols.

The DIS could also be used in longitudinal studies on the impact of diagnosis over time or at different periods during treatment. Although time since diagnosis was investigated in this study, this was between participants which affords less precise comparison.

In this study, public stigma was incorporated into the DIS as an aspect of diagnosis impact. However, it may be helpful to investigate the relationship between public stigma and diagnosis impact as it is possible that a high proportion of the negative impact of diagnosis is due to stigma (Laird et al., 2009; Link & Phelan, 2013; Manderscheid et al., 2010). A large correlation would be expected with the DRSS subscale as it is believed to reflect internalised stigma while it is likely that high levels of experienced public stigma would be associated with low scores on the HoD subscale.

Finally, research comparing the impact of mental health difficulties on self-stigma and the impact of diagnosis on self-stigma (using the DIS) may help illuminate the precise root of self-stigma.

4.6. Implications for Clinical Practice

The current study has generated some important information which is relevant to clinical practice in psychiatry and psychological therapies. Among the most salient findings of the current study is the variation in diagnosis impact depending on the particular diagnosis a service-user receives. As those with personality disorder diagnoses report significantly higher self-stigma due to diagnosis, it may be helpful to address self-stigma when communicating these diagnoses as suggested by Milton and Mullan (2015). It may also be advisable for clinicians working with people with these diagnoses to enquire about the effect of diagnosis on their self-view particularly to identify any misconceptions these service-users may have about their diagnosis. Self-stigma interventions have shown good efficacy in previous studies and may be an important part of psychological treatment of those diagnosed with personality disorders (Tsang et al., 2016).

The relatively low HoD scores of participants with personality disorder diagnoses, in support of previous research, suggest that these diagnoses have questionable functional value for recipients. It is important for clinicians to be mindful of this when considering ascribing these diagnoses as it may be advisable to manage recipient expectations of practical benefits of diagnosis.

Communication of and about diagnoses was found to have a strong association with diagnosis impact. Based on previous research, clinicians should ensure that they relay clear and adequate information to service-users. Indirect communication of diagnoses should also be avoided as this has been reported in previous studies as particularly unhelpful (Callard, 2014; Castillo, Allen, & Coxhead, 2001; Magliano et al., 2008; Outram et al., 2014; Pitt et al., 2009; Stalker et al., 2005; Thomas et al., 2013).

Findings suggest that those with multiple diagnoses are particularly likely to experience diagnosis-related self-stigma and that this grows with increasing numbers of diagnoses. Clinicians should be particularly mindful of the potential for self-stigma when communicating second or additional diagnoses. It may be helpful to speak to service-users about the meaning of receiving more diagnoses in order to identify and address stigmatising beliefs or misconceptions.

Current findings suggest that self-stigma does not decrease significantly over time. This suggests that clinician attention to this aspect of diagnosis impact may be important throughout treatment, perhaps especially for those who have been shown to experience high self-stigma due to diagnosis.

Results suggest that it may be particularly important for psychiatrists to discuss diagnosis-related self-stigma when communicating diagnoses. Although results of this study may be confounded by symptom severity or diagnosis type, it remains that those diagnosed by psychiatrists show comparatively high levels of diagnosis-related self-stigma suggesting that these clinicians may be particularly well placed to target this negative effect of diagnosis.

4.7. Clinical Applications of the DIS

The DIS is a general measure of the impact of psychiatric diagnosis on recipients. Its broad nature affords flexibility and it can be used by mental health professionals of any discipline, and in both public and private settings (See Appendix T for the clinical version of the DIS). It is envisaged that the DIS will serve as a tool to encourage collaborative dialogue in relation to individuals' experience of their diagnoses. Perceived power difference between clinicians and service users is commonly reported by service-user participants in previous studies on psychiatric

diagnosis (Hayne, 2003; Horn et al., 2007; Thomas et al., 2013). This scale has the potential to create a more balanced power dynamic within clinical encounters by emphasising the importance of the service-user perspective.

It is of course possible to have very fruitful conversations about diagnosis with clients and patients without the use of a clinical tool or questionnaire. However, offering such a tool to the service-user may give them an opportunity to think about aspects of their diagnosis which they are less conscious of in their day to day lives. It may also allow them to communicate experiences that it is initially difficult to share verbally. This may be particularly pertinent if the clinician enquiring about the impact of diagnosis also gave the diagnosis. It is plausible that an individual may feel uncomfortable describing the negative effects of diagnosis to the diagnosing professional verbally in the first instance. In addition, some services and practitioners give clients and patients forms to complete prior to appointments. The DIS can be completed without a clinician present which may give clients more of an opportunity to reflect on their experience of diagnosis than a direct conversation would.

The DIS could also be used in initial assessments for therapy. It may be helpful for therapists to have a sense of a potential client's relationship with their diagnosis, particularly in the case of those with personality disorder diagnoses. The use of diagnostic terminology may be particularly helpful or unhelpful for certain clients and knowledge of this in the early stages of therapy may aid the development of the therapeutic relationship.

The DIS could help diagnosing professionals to establish how diagnoses are received and get a sense of their initial impact in post-diagnostic reviews or sessions. This may allow any misunderstandings or misconceptions to be addressed and could

potentially inform the ongoing use (or avoidance) of diagnostic terminology with individual clients and patients.

As time is often very limited in clinical sessions and settings, particularly in the public sector, the DIS has the advantage of being a concise measure which should take no longer than five to ten minutes to complete, making it practical for clinical use.

4.8. Implications for Counselling Psychology

Owing to the humanistic roots of counselling psychology, its practitioners have not traditionally been closely linked to psychiatric classification and diagnosis. However, with counselling psychologists increasingly being employed by public healthcare services where the medical model of psychopathology is dominant, diagnosis is becoming more relevant to counselling psychologists (Douglas, 2010). On referral, many of their clients and patients may have prior diagnoses or they may be expected to give diagnoses by service-users and/or services (Davies et al., 2017). A number of authors highlight an incongruence between the humanistic origins of counselling psychology and diagnostic classification and many counselling psychologists report feeling ambivalent about diagnosis (Craven & Coyle (2007). It is hoped that use of the DIS will reduce any incongruence felt by practitioners as it prioritises the client perspective and attempts to promote service-user agency, thus somewhat bridging the divide between the medical model and the humanistic tradition. In line with the scientist-practitioner aspect of the counselling psychologist's professional identity, this study makes a potential contribution to evidence-based practice. Up to now, there has been no measure of diagnosis impact and thus no statistically generalisable information on the phenomenon. The practice of giving diagnoses cannot be said to be evidence-based if there is no research on the service-user experience of it. It is hoped that the

findings of the current research will be used by counselling psychologists, and mental health professionals in general, when they are considering communication of diagnostic labels.

Chapter 5:
Summary

The aim of this study was the creation and validation of a self-report measure of the impact of psychiatric diagnoses on recipients. The scale, created based on previous qualitative literature, a focus group and expert rating, was assessed using the Three-Step Test Interview protocol and psychometric exploration. The 19-item scale showed high reliability on both subscales, convergence with the PFC, SWLS and single-item diagnosis helpfulness measure and reasonable divergence with the SDS-17, CORE-10, and PANAS. Two dimensions of diagnosis impact were identified; Helpfulness of Diagnosis and Diagnosis-Related Self-Stigma.

The criterion validity investigation showed that higher levels of Helpfulness of Diagnosis were associated with receiving treatment due to diagnosis, perception of this treatment as helpful, perception that one's diagnosis is correct, and anxiety disorder diagnoses. Lower levels of Helpfulness of Diagnosis were associated with personality disorder diagnoses. Additionally, increasing age and duration since diagnosis was associated with lower Helpfulness of Diagnosis. In terms of criterion validity, higher levels of Diagnosis-Related Self-Stigma were associated with receiving treatment, perception that treatment is unhelpful, perceived incorrect diagnosis, multiple diagnoses, personality disorder diagnoses. Higher Diagnosis-Related Self-Stigma was also associated with increasing number of diagnoses and diagnosing professional type. Lower levels of Diagnosis-Related Self-Stigma were associated with anxiety and depressive disorder diagnoses, and receiving a diagnosis from a general practitioner. No significant association was found between diagnosis impact and gender, mental health professional status, or receipt of formal assistance in employment or education/training.

The DIS is the first measure of the impact of psychiatric diagnoses on people who receive them, therefore this is the first study to use a specialised scale to investigate the varied nature of experience of diagnosis between people. The DIS has been designed to be used clinically and for research purposes. Given the centrality of psychiatric diagnosis in mental healthcare and its importance to recipients, it has potential to make a valuable contribution to both spheres.

Clinically, it is hoped that it will encourage conversations between practitioners and service-users about the effect of diagnostic labels and facilitate collaborative decision-making as a result. This research, particularly the criterion validity results, may also be useful for practitioners who are deliberating about ascribing diagnostic labels to individual service-users. Given the centrality of psychiatric diagnosis in mental healthcare and its importance to recipients, the DIS has the potential to make a valuable contribution to clinical practice and mental health research.

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Appendices

Appendix A: Literature Search Terms

Anxiety

Bipolar disorder

Benefits of mental health diagnosis

Benefits of psychiatric diagnosis

Depression

Diagnosis

Diagnostic classification

Diagnostic and Statistical Manual of Mental Disorder

Eating disorder

Impact of mental health diagnosis

Impact of psychiatric diagnosis

Impact of mental illness

International Classification of Disease

Mental disorder

Mental health diagnosis

Mental health service user

Mental health stigma

Mental illness

Mental illness diagnosis

Personality disorder

Psychiatric diagnosis

Psychiatric disorder

Schizophrenia

Service user

Stigma

Value of psychiatric diagnosis

Value of mental health diagnosis

Appendix B: Ethical Approval for the Item Pool Development and the Scale Development Study

Item pool development ethical approval

Dear Niamh,

Applicant: **Niamh O'Connor**
Title: **Item generation and rating for the Diagnosis Impact Scale (DIS)**
Reference: **PSYC 16/ 236**
Department: **Psychology**

Many thanks for your response and the amended documents. Further to the email below, under the procedures agreed by the University Ethics Committee I am pleased to advise you that, apart from the minor conditions below, your Department has confirmed that all conditions for approval of this project have now been met. As these are minor conditions you may proceed with your research. We do not require anything further in relation to this application (other than the copy of the scale when available).

Minor Conditions:

i. Please let us have a copy of the final version of the Diagnosis Impact Scale once developed (we understand that this should be available by December 2016).
ii. I am pleased to confirm that the risk assessment for your project has been reviewed and approved by the Health, Safety & Environment Department. Two minor conditions have been recommended to this:
    a) Please ensure that the date on page 1 is the date or date range that the research will be carried out. This cannot be a date prior to approval.
    b) Please ensure that the supervisor signs the Lead assessor at the end of the document, when the applicant is student.

    As these are only minor conditions it is assumed that you will adhere to these conditions for approval and therefore we do not need to see the revised risk assessment.

Please note that on a standalone page or appendix the following phrase should be included in your thesis:

The research for this project was submitted for ethics consideration under the reference PSYC 16/ 236 in the Department of Psychology and was approved under the procedures of the University of Roehampton's Ethics Committee on 31.08.16.

Please Note:

- **This email confirms that all conditions have been met and thus confirms final ethics approval (it is assumed that you will adhere to any minor conditions still outstanding).**
- **University of Roehampton ethics approval will always be subject to compliance with the University policies and procedures applying at the time when the work takes place. It is your responsibility to ensure that you are familiar and compliant with all such policies and procedures when undertaking your research.**
- **Please advise us if there are any changes to the research during the life of the project. Minor changes can be advised using the Minor Amendments Form on the Ethics Website, but substantial changes may require a new application to be submitted.**

Many thanks,

Jan

Jan Harrison
Ethics Officer
Research Office
University of Roehampton | London | SW15 5PJ
jan.harrison@roehampton.ac.uk| www.roehampton.ac.uk
Tel: +44 (0) 20 8392 5785

Scale development ethnical approval

Applicant: **Niamh O'Connor**
Title: **The development and validation of the Diagnosis Impact Scale (DIS) and an exploration of possible predictors of the impact of psychiatric diagnosis.**
Participant facing: Interviews for the development of the Diagnosis Impact Scale
Diagnosis Impact Scale development survey
Reference: **PSYC 16/ 237**
Department: **Psychology**

Many thanks for advising that you have renewed your DBS. Under the procedures agreed by the University Ethics Committee I am pleased to advise you that your Department has confirmed that all conditions for approval of this project have now been met. We do not require anything further in relation to this application (but please let us have copies of the documents referred to in the minor condition below).

Minor Condition:

Please let us have a copy of the final version of the Diagnosis Impact Scale once developed (we understand that this should be available by December 2016) and a sample of focused interview questions that may be developed on the basis of this).

Please note that on a standalone page or appendix the following phrase should be included in your thesis:

The research for this project was submitted for ethics consideration under the reference PSYC 16/ 237 in the Department of Psychology and was approved under the procedures of the University of Roehampton's Ethics Committee on 16.11.16.

Please Note:

- **This email confirms that all conditions have been met and thus confirms final ethics approval (it is assumed that you will adhere to any minor conditions still outstanding, therefore we do not require a response to these).**
- **University of Roehampton ethics approval will always be subject to compliance with the University policies and procedures applying at the time when the work takes place. It is your responsibility to ensure that you are familiar and compliant with all such policies and procedures when undertaking your research.**

- **Please advise us if there are any changes to the research during the life of the project. Minor changes can be advised using the Minor Amendments Form on the Ethics Website, but substantial changes may require a new application to be submitted.**

Many thanks,

Jan

Jan Harrison
Ethics Officer
Research Office
University of Roehampton | London | SW15 5PJ
jan.harrison@roehampton.ac.uk| www.roehampton.ac.uk
Tel: +44 (0) 20 8392 5785

Appendix C: Focus Group Recruitment Materials, Information Sheet, Consent Form, and Debriefing Form

Focus group participant recruitment email to PsychD colleagues

Hi all,

I hope you're all over the stress of the assignments and enjoying the summer. As some of you know my research project is developing a scale to measure the impact of receiving a psychiatric diagnosis. Ultimately the hope is that the scale will be well enough developed to be used as a clinical tool to open up discussions between patients and psychiatrists/psychologists on the label they've been given rather than them being the object in the scenario. At this stage I am looking for some consultants to help me create the scale in a focus group. I will be making up a group of consultants that will be bringing a mixture of expertise as people who have received diagnoses and/or mental health professionals.

Which is where you come in! I'm emailing to ask for your help to join this group.

This will involve…… one session of an hour and a half or some online rating of items.

So I'm emailing you to check, would anyone consider helping me with developing my item pool? It won't be necessary to disclose anything about your own personal experience (if you would be uncomfortable with that) rather what you think are important and relevant aspects of receiving a diagnosis, including any impact this may have.

I would be delighted and so grateful if ye would consider helping me with any of the following (I will provide payment in the form of baked goods, or whatever your poison is and also happy to help with anything you need for your project):

1. The first step will be developing an item pool which in itself involves two stages with two separate groups;

a) a focus group to discuss what aspects/consequences of diagnosis should be included in the scale in order to determine the impact (90 mins in uni)

b) a group to come up with items based on the information from the focus group (90 mins in uni)

2. After this the items will be rated based on their relevance to diagnosis impact and general formulation of the items themselves which will be an online survey on Qualtrics

Again, I would really appreciate any help with this! At this point I'm keeping this email to our class only so please don't forward it to others.

Thanks,

Niamh

Focus group participant recruitment email to University of Roehampton School of Psychology lecturers

Dear lecturers,

I am a second year PsychD student and as my doctoral research project I will be developing a scale to measure the impact of psychiatric diagnoses on those who receive them. The research in this area from a service user/client perspective is very limited and the quantitative research is even more so.
Ultimately the hope is that the scale will be well enough developed to be used as a clinical tool to open up discussions between patients and psychiatrists/psychologists on the label they've been given rather than them being the object in the scenario.

At this stage I am looking for some consultants to help me create the scale in a focus group. I will be making up a group of consultants that will be bringing a mixture of expertise; people who have received diagnoses and/or mental health professionals.

Which is where you come in! I'm emailing to ask you to join this group.
This will involve…… one session of an hour and a half or some online rating of items.

I would be delighted and so grateful if you would consider helping me with any of the following:

1. The first step will be developing an item pool which in itself involves two stages with two separate groups ;
a) a focus group to discuss what aspects/consequences of diagnosis should be included in the scale in order to determine the impact (90 mins on campus)
b) a group to come up with items based on the information from the focus group (90 mins on campus)

2. After this the items will be rated based on their relevance to diagnosis impact and general formulation of the items themselves which will be an online survey on Qualtrics.

If you are interested in participating in the focus group, item creation group or in rating the items please reply to this email to discuss dates of groups etc.

Again, I would really appreciate any help with this!

Kind regards,

Niamh

Focus group information sheet

University of Roehampton London

INFORMATION SHEET

Discussion of subscales for the Diagnosis Impact Scale (DIS)

This study has been developed by counselling psychology researchers at the University of Roehampton, UK.

The aim of this research is to develop a measure that can assess the impact of psychiatric diagnosis on those who receive them.

To achieve this, we would be grateful if you could participate in a 90 minute discussion group. The discussion group will be comprised of 3-5 individuals, both PsychD lecturers and 3rd year PsychD students.

The purpose of the discussion group is to ascertain which aspects of psychiatric diagnosis are central to the measurement of its impact.

The group discussion will take place at the University of Roehampton premises. It will be audio recorded and written notes will be taken.

No one, other than the researchers, will see your individual responses, and they will be treated as entirely anonymous. No names or identifying information will be collected. Paper data will be stored in a locked cabinet at the University of Roehampton and electronic data will be kept on a password protected computer at the University of Roehampton.

The benefit of participating in this research is that you can help to contribute towards the development of a new measure of the impact of psychiatric diagnosis which will increase the body of knowledge about the experiences of service users. Taking part in the research may be interesting for you in helping you to reflect on your own experience of psychiatric diagnosis or that of your clients/patients.

The disadvantage of taking part in this study is that there may be a small possibility that thinking about psychiatric diagnosis evokes some distressing feelings.

If this occurs, you can alert the Principal Investigator, Niamh O' Connor (leading the discussion group) who can help you identify the most appropriate source of support. Alternatively you can contact your GP or a mental health helpline, the contact details for two such helplines are listed below.

MIND **Samaritans**

Infoline: 0300 123 3393
Lines are open from 9am to 6pm
Monday to Friday (except bank holidays)

Free Helpline: 116 123
Lines are open 24 hours 7 days per week

There is no payment (other than refreshments!) associated with taking part in this study. You can withdraw from this study at any time without giving a reason, you will not be adversely affected.

This project has been approved under the procedures of the University of Roehampton Ethics Committee (Ref: PSYC 16/236).

With the exception of audio recordings, data from this study will be stored in anonymised format and will be used for one or more journal articles. It may also be used for other educational or teaching purposes. In any publications, your individual responses will not be identifiable in any way.

Please note: if you have a concern about any aspect of your participation or any other queries please raise this with the investigator (or if the researcher is a student you can also contact the Director of Studies). However, if you would like to contact an independent party please contact the Head of Department.

Principal Investigator Contact Details:

Niamh O' Connor
Department of Psychology
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Holybourne Avenue
London SW15 4JD
Email:oconnorn@roehampton.ac.uk
Telephone: +44 (0) 7860 841577

Director of Studies Contact Details:

Prof. Mick Cooper
Department of Psychology
University of Roehampton
Holybourne Avenue
London SW15 4JD
Email: mick.cooper@roehampton.ac.uk
Telephone: 0208 392 3741

Head of Department Contact Details:

Dr. Diane Bray
Department of Psychology
University of Roehampton
Holybourne Avenue
London SW15 4 JD
Email: d.bray@roehampton.ac.uk
Telephone: 0208 392 3741

Focus group consent form

University of Roehampton London

PARTICIPANT CONSENT FORM

Discussion of subscales for the Diagnosis Impact Scale (DIS)

Brief Description of Research Project, and What Participation Involves:

In this study we aim to develop a new scale to measure the impact of psychiatric diagnosis on service users. This part of the scale development involves a discussion group to ascertain which aspects of psychiatric diagnosis are central to the measurement of its impact. The discussion group will take place at the University of Roehampton premises. Group discussions are audio recorded, written notes are taken and they will take up to 90 minutes. The discussion group will be comprised of 3 to 5 individuals, both PsychD lecturers and 3rd year PsychD students.

Principal Investigator Contact Details:

Niamh O' Connor
Department of Psychology
University of Roehampton
Holybourne Avenue
London SW15 4JD
Email: oconnorn@roehampton.ac.uk
Telephone: +44 (0) 7860 841577

Consent Statement:

I agree to take part in this research, and am aware that I am free to withdraw at any point without giving a reason, although if I do so I understand that my data might still be used in a collated form. I understand that the information I provide will be treated in confidence by the investigator and that my identity will be protected in the publication of any findings, and that data will be collected and processed in accordance with the Data Protection Act 1998 and with the University's Data Protection Policy.

Name ……..

Signature ……

Date ……

Paper data will be stored in a locked cabinet at the University of Roehampton and electronic data will be kept on a password protected computer at the University of Roehampton. Any identifying information will be removed from all data before storage and only the researcher, note-taker and research supervisors will see your responses. Informants will not be named in any published material.

If you wish to withdraw from the study, please contact the investigator with the ID number which you will receive on a Debriefing Form after the discussion group. The data may still be used/ published in an aggregate form.

Please note there is no compulsion to participate. Participation or withdrawal from the study **will not** affect your relationship with the University of Roehampton or any services you are in receipt of.

Please note: if you have a concern about any aspect of your participation or any other queries please raise this with the investigator (or if the researcher is a student you can also contact the Director of Studies.) However, if you would like to contact an independent party please contact the Head of Department.

Director of Studies Contact Details:

Prof. Mick Cooper
Department of Psychology
University of Roehampton
Holybourne Avenue
London SW15 4JD
Email: mick.cooper@roehampton.ac.uk
Telephone: 0208 392 3741

Head of Department Contact Details:

Dr. Diane Bray
Department of Psychology
University of Roehampton
Holybourne Avenue
London SW15 4JD
Email: d.bray@roehampton.ac.uk
Telephone: 0208 392 3741

Focus group debriefing form

University of Roehampton London

DEBRIEFING FORM

Discussion of subscales for the Diagnosis Impact Scale (DIS)

In this study we aim to develop a new scale to measure the impact of psychiatric diagnosis on service users. This part of the study involves participating in a 90 minute discussion group of 3 to 5 individuals. The purpose of this discussion group is to determine which aspects of psychiatric diagnosis should be included in a scale to measure its impact on service users.

Thank you very much for your participation!

ID number:

If you wish to withdraw from the study, please contact the investigator with the ID number which appears above. The data may still be used in an aggregate form.

If you have a concern about any aspect of your participation or any other queries please raise this with the investigator (or if the researcher is a student you can also contact the Director of Studies). However, if you would like to contact an independent party please contact the Head of Department.

Principal Investigator Contact Details:

Niamh O' Connor
Department of Psychology
University of Roehampton
Holybourne Avenue
London SW15 4JD
Email: oconnorn@roehampton.ac.uk
Telephone: +44 (0) 7860 841577

Director of Studies Contact Details:
Prof. Mick Cooper
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University of Roehampton
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Email: mick.cooper@roehampton.ac.uk
Telephone: 0208 392 3741

Head of Department Contact Details:
Dr. Diane Bray
Department of Psychology
University of Roehampton
Holybourne Avenue
London SW15 4JD
Email: d.bray@roehampton.ac.uk
Telephone: 0208 392 3627

If you experienced distress while participating in the study please contact the Principal Investigator, your GP or a mental health helpline (contact details for two such helplines are listed below).

MIND

Infoline: 0300 123 3393
Lines are open from 9am to 6pm
Monday to Friday (except bank holidays).

Samaritans

Free Helpline: 116 123
Lines are open 24 hours 7 days per week.

Appendix D: Online Item Rating Recruitment, Information Sheet, Consent Form, Debriefing Form, and Results

Online item rating participant recruitment email

Dear all,

Thank you very much for your interest in my study on the impact of psychiatric diagnosis on those who receive them, I greatly appreciate it. Apologies if you have already seen this email. I don't mean to pester you, but as many of you were on annual leave when I sent it in August, I thought it might be worth re-sending. I would really appreciate your help with this stage of the scale development if you can spare the time.

At this stage a pool of 109 items for the Diagnosis Impact Scale (DIS) has been created. I would now like to ask you to rate the items based on relevance to a scale measuring the impact of psychiatric diagnosis and also their general formulation and clarity as items. Below is a link to the item pool on Qualtrics:

https://roehamptonpsych.az1.qualtrics.com/jfe/form/SV_834hm4gWLbwLcmp

Item rating should take no longer than 30 minutes. I have attached the information sheet and consent form for your perusal. These will appear at the beginning of the online item rating survey.
If you have a concern about any aspect of your participation or any other queries please raise this with me or the Director of Studies. However, if you would like to contact an independent party please contact the Head of Department.

Principal Researcher Contact Details:
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Telephone: 07860 841577

Director of Studies Contact Details:
Prof. Mick Cooper
Department of Psychology
University of Roehampton
Holybourne Avenue
London SW15 4JD
Email: mick.cooper@roehampton.ac.uk
Telephone: 0208 392 3741

Head of Department Contact Details:
Dr. Diane Bray
Department of Psychology
University of Roehampton
Holybourne Avenue
London SW15 4 JD
Email:d.bray@roehampton.ac.uk
Telephone: 0208 392 3627

Thank you again for your willingness to contribute to this research.

Kind regards,
Niamh

Online item rating information sheet

University of Roehampton London

INFORMATION SHEET

Item rating for the Diagnosis Impact Scale (DIS)

This study has been developed by counselling psychology researchers at the University of Roehampton, UK.

The aim of this research is to develop a measure that can assess the impact of psychiatric diagnosis on those who receive them.

To achieve this, we would be grateful if you could participate in online rating of the items created for the DIS, it should take no longer than 30 minutes.

The purpose of item rating is to ascertain which items are most suitable for inclusion in the DIS.

No one, other than the researchers, will see your individual responses, and they will be treated as entirely anonymous. No names or identifying information will be collected. Electronic data will be kept on a password protected computer at the University of Roehampton.

The benefit of participating in this research is that you can help to contribute towards the development of a new measure of the impact of psychiatric diagnosis which will increase the body of knowledge about the experiences of service users. Taking part in the research may be interesting for you in helping you to reflect on your own experience of psychiatric diagnosis or that of your clients/patients.

The disadvantage of taking part in this study is that there may be a small possibility that thinking about psychiatric diagnosis evokes some distressing feelings.

If this occurs, you can alert the Principal Investigator, Niamh O' Connor (contact details below) who can help you identify the most appropriate source of support. Alternatively, you can contact your GP or a mental health helpline, the contact details for two such helplines are listed below.

MIND

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Samaritans

Free Helpline: 116 123
Lines are open 24 hours 7 days per week

There is no payment associated with taking part in this study. You can withdraw from this study at any time without giving a reason, you will not be adversely affected.

This project has been approved under the procedures of the University of Roehampton Ethics Committee (PSYC 16/236).

Data from this study will be stored in anonymised format and will be used for one or more journal articles. It may also be used for other educational or teaching purposes. In any publications, your individual responses will not be identifiable in any way.

Please note: if you have a concern about any aspect of your participation or any other queries please raise this with the investigator (or if the researcher is a student you can also contact the Director of Studies). However, if you would like to contact an independent party please contact the Head of Department.

Principal Investigator Contact Details:

Niamh O' Connor
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University of Roehampton
Holybourne Avenue
London SW15 4JD
Email: oconnorn@roehampton.ac.uk
Telephone: +44 (0) 7860 841577

Director of Studies Contact Details:

Prof. Mick Cooper
Department of Psychology
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Telephone: +44 (0) 208 392 3627

Online item rating consent form

University of Roehampton London

PARTICIPANT CONSENT FORM

Item rating for the Diagnosis Impact Scale (DIS)

Brief Description of Research Project, and What Participation Involves:

In this study, we aim to develop a new scale to measure the impact of psychiatric diagnosis on service users. This part of the scale development involves rating of items to ascertain which items are most suitable for inclusion in the DIS. Rating of items will be online and will take up to 30 minutes.

Principal Investigator Contact Details:

Niamh O' Connor
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University of Roehampton
Holybourne Avenue
London SW15 4JD
Email: oconnorn@roehampton.ac.uk
Telephone: +44 (0) 7860 841577

Consent Statement:

I agree to take part in this research, and am aware that I am free to withdraw at any point without giving a reason, although if I do so I understand that my data might still be used in a collated form. I understand that the information I provide will be treated in confidence by the investigator and that my identity will be protected in the publication of any findings, and that data will be collected and processed in accordance with the Data Protection Act 1998 and with the University's Data Protection Policy.

- Yes
- No

If you wish to withdraw from the study, please contact the investigator with the ID number which you will be presented with a Debriefing Form after the item rating. The data may still be used/ published in an aggregate form.

Electronic data will be kept on a password protected computer at the University of Roehampton. Any identifying information will be removed from all data before storage and only the researcher and research supervisors will see your responses. Informants will not be named in any published material.

Please note there is no compulsion to participate. Participation or withdrawal from the study **will not** affect your relationship with the University of Roehampton or any services you are in receipt of.

Please note: if you have a concern about any aspect of your participation or any other queries please raise this with the investigator (or if the researcher is a student you can also contact the Director of Studies.) However, if you would like to contact an independent party please contact the Head of Department.

Director of Studies Contact Details:

Prof. Mick Cooper
Department of Psychology
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Holybourne Avenue
London SW15 4JD
Email: mick.cooper@roehampton.ac.uk
Telephone: +44 (0) 208 392 3741

Head of Department Contact Details:

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Department of Psychology
University of Roehampton
Holybourne Avenue
London SW15 4JD
Email: d.bray@roehampton.ac.uk
Telephone: +44 (0) 208 392 3627

Online item rating debriefing form

University of Roehampton London

DEBRIEFING FORM

Item rating for the Diagnosis Impact Scale (DIS)

In this study we aim to develop a new scale to measure the impact of psychiatric diagnosis on service users. This stage involves online rating of scale items to determine their relevance to the scale and also assess the overall composition of each item.

Thank you very much for your participation!

ID number:

If you wish to withdraw from the study, please contact the investigator with the ID number which appears above. The data may still be used in an aggregate form.

Please note: if you have a concern about any aspect of your participation or any other queries please raise this with the investigator (or if the researcher is a student you can also contact the

Director of Studies). However, if you would like to contact an independent party please contact the Head of Department.

Principal Investigator Contact Details:

Niamh O' Connor
Department of Psychology
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If you would like to contact an independent party, you can contact:

Director of Studies Contact Details:
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Online item rating results

Table 1. Online Item Rating Results

108 Items	Overall average item rating

My diagnosis has helped me to understand myself better	3.8
I have kept my diagnosis a secret from most people in case they treat me differently	3.8
I have felt my diagnosis helps others to understand me	3.7
My problems have had more recognition from others because of my diagnosis	3.7
My diagnosis has given me more independence	3.6
My diagnosis has had a negative effect on my career	3.6
I have felt worse about myself because of my diagnosis	3.5
It has felt like people expect me to behave a certain way because of my diagnosis	3.5
It has felt like people view me as dangerous because of my diagnosis	3.5
People have seemed overprotective of me because of my diagnosis	3.5
I have felt ashamed of my diagnosis	3.5
I have felt my diagnosis makes it more difficult to get a job	3.5
Because of my diagnosis, I have thought of my problems as being part of my illness rather than part of me	3.4
I have felt that my diagnosis defines me	3.4
My diagnosis has made me feel more normal	3.4
My diagnosis has made me feel like I'm not the only one who feels like I do	3.4
My diagnosis has had little meaning for me	3.4
I have lost people in my life due to my diagnosis	3.4
I have felt marginalised because of my diagnosis	3.4
I have felt I am less likely to be promoted at work because of my diagnosis	3.4
My diagnosis has helped me to access specialised care	3.4
My diagnosis has given me access to professional help	3.4
My diagnosis has made me feel I am weak	3.3
People have treated me like I'm fragile because of my diagnosis	3.3

My diagnosis has made it more difficult to access education	3.3
I have felt that my diagnosis means I am flawed	3.3
My diagnosis has made me feel I can be helped	3.3
My diagnosis has given me hope /My diagnosis has made me feel positive about the future	3.3
It has felt like people are sympathetic toward me because of my diagnosis	3.3
My diagnosis has helped me to look for information about my difficulties	3.3
People have forced me to have treatment because of my diagnosis	3.3
My diagnosis has made my mental health difficulties worse	3.3
My diagnosis has helped me to feel better	3.3
My diagnosis has meant that I can take breaks from education when I need to	3.3
I have wished I had not been diagnosed	3.3
My diagnosis has made me think I am crazy	3.2
My diagnosis has given me more clarity about my difficulties	3.2
My diagnosis has made me confused about my difficulties	3.2
I have been glad I received my diagnosis	3.2
I have felt part of a community because of my diagnosis	3.2
My diagnosis has helped me to get time off	3.2
My diagnosis has made me feel I didn't know myself	3.2
My diagnosis has made me feel safe	3.2
I have felt I am seen as weak because of my diagnosis	3.2
I have felt people are patronising toward me because of my diagnosis	3.2
I have had to take medicine because of my diagnosis	3.2
As a result of my diagnosis I have felt healthcare professionals could understand me better	3.2
It has felt like people have excuse my behaviour because of my diagnosis	3.1
Due to my diagnosis I have been more willing to seek professional help	3.1

My diagnosis has made me feel special	3.1
My diagnosis has made me feel trapped	3.1
I have felt my diagnosis is fixed, I can't get rid of it /I have felt I will always have my diagnosis, it cannot be changed	3.1
I have felt happier since getting my diagnosis	3.1
My diagnosis has worried me	3.1
My wellbeing has seemed less important to others since I received my diagnosis	3.1
My diagnosis has made it difficult to access the mental health services I wanted	3.1
Because of my diagnosis I have been hopeful that I can be helped	3.1
My diagnosis has made me more willing to ask my friends for help	3.1
My diagnosis has made no difference to my mental health difficulties	3.1
I have felt people view me differently to others on my course because of my diagnosis	3.1
My diagnosis has made me feel I have been put in a box	3.0
My diagnosis has motivated me to get better	3.0
Because of my diagnosis, I have felt my mental health difficulties are more the healthcare professionals' responsibility than mine	3.0
My diagnosis has validated my experience	3.0
My diagnosis has been comforting	3.0
It has felt like my loved ones understand me better because of my diagnosis	3.0
It has felt like healthcare professionals are in control of my life because of my diagnosis	3.0
My diagnosis has led to having less control over my life /I have had less choice in what I do because of my diagnosis	3.0
My diagnosis has made me more dependent on others	3.0
My diagnosis has made me more willing to ask for help from loved ones	3.0
My friends have understood me better because of my diagnosis	2.9

My diagnosis has caused an improvement in my general wellbeing	2.9
Because of my diagnosis, I have not had to work	2.9
It has felt like people with the same diagnosis understood me	2.9
My life has revolved around my diagnosis	2.9
It has felt like healthcare professionals do not take my questions seriously because of my diagnosis	2.9
As a result of my diagnosis, I have had more faith in healthcare professionals	2.9
I have felt people are reluctant to do group exercises/projects with me because of my diagnosis	2.9
My diagnosis has made me feel my difficulties are recognised	2.9
It has felt like my diagnosis helps people to understand that I'm not well	2.9
I have felt I need to compensate for my diagnosis with my behaviour	2.9
My diagnosis has given me more power over my difficulties	2.9
It has felt like people view me differently from others at work because of my diagnosis	2.9
My diagnosis has meant that changes were made to facilitate me in education/training	2.9
I have used my diagnosis to blame those close to me for my problems	2.8
My diagnosis has made me feel less individual	2.8
My diagnosis has made me worried that I would be dangerous in the future	2.8
My diagnosis has made me feel broken	2.8
I wouldn't know who I was without my diagnosis	2.8
My diagnosis has clarified things about my experience	2.8
My diagnosis has made me angry with my loved ones	2.8
My diagnosis has allowed me to take breaks from work	2.8
My diagnosis has helped me to access mental health services	2.8
My diagnosis has helped with my recovery	2.8
My diagnosis has allowed me to avoid taking responsibility for myself/I have blamed my diagnosis for things that I do	2.8

My diagnosis has made me feel less anxious about the symptoms I experience/ My diagnosis has made me feel less anxious about my internal experience	2.7
It has felt like people use my diagnosis to explain ordinary things I do	2.7
My diagnosis has meant changes are made to facilitate me at work	2.7
My diagnosis has caused problems with my therapy	2.7
My diagnosis has replaced a part of my personality /My diagnosis explained what I thought was a part of my personality	2.7
My diagnosis has made me feel validated	2.7
It has felt like my diagnosis causes people interpret ordinary things I have done as unusual	2.7
My diagnosis has prevented me from getting more information about my condition from healthcare professionals	2.6
I have used my diagnosis to avoid doing things that frighten me	2.5
My diagnosis has made my problems feel more defined	2.5
My diagnosis has made me feel grounded/contained	2.4
I have felt that my diagnosis means there are times when I cannot cope but does not define me	2.1
It has felt like my diagnosis distracts healthcare professionals from other mental health problems I have / My diagnosis has masked other problems I have	1.7

Appendix E: TSTI Recruitment, Information Sheet, Consent Form, Debriefing Form, and Results

TSTI participant recruitment email

Dear Sir/Madam,

Thank you very much for your interest in our research, it is greatly appreciated.

We (Niamh O' Connor, Prof. Mick Cooper and Dr. Jacqueline Hayes) are currently recruiting up to 20 participants for the pre-test phase of the research. This involves participants being

interviewed one-to-one to elicit their responses to the scale items and determine their suitability for inclusion in the scale. Interviews will take place at the University of Roehampton, UK, at an alternative location which is convenient for the participant (suitable for confidential discussion) or via Skype for participants who are unable to travel.

All interview material will be treated confidentially and stored in a locked cabinet or on a password protected computer at the University of Roehampton, UK.

Completion of the interview should not take longer than one hour.

This project has been approved under the procedures of the University of Roehampton's Ethics Committee (Ref: PSYC 16/237).

If you are willing to help us we would be very grateful if you could display a poster in your branches, add information about the study to your website and/or send the message at the bottom of this email to your service users. Any help to recruit participants would be hugely appreciated. We have attached the participant recruitment poster for your information.

If you have any questions regarding the study, please do not hesitate to contact the Principal Investigator:

Niamh O' Connor
Department of Psychology
University of Roehampton
Holybourne Avenue
London SW15 4JD
Email: oconnorn@roehampton.ac.uk
Telephone: +44 (0) 7393 709213

Warm regards,
Niamh

Dear service user/staff member,

We are forwarding on an email to you regarding a study that you may be interested in participating in.

The University of Roehampton, UK, is currently conducting research into the impact of mental health diagnoses on individuals who receive them. The aim of the study is to develop a questionnaire on the impact of mental health diagnosis and also explore some factors which may affect how service users feel about their diagnosis (for example, how a diagnosis is communicated, time since diagnosis, demographic variables).

The scale will focus on the impact of mental health diagnosis from the service user's perspective as there is a lack of research on this topic from a service user perspective. There is currently no statistically generalisable evidence on the impact of mental health diagnoses on those who receive them. Additionally, it is hoped that the use of this scale in clinical practice will empower service users and encourage a dialogue between service users and professionals on the experience of receiving and having a mental health diagnosis.

We are currently recruiting up to 20participants for one of the initial phases of the scale development which involves a one-to-one interview to elicit reactions to the scale items and

determine their suitability for inclusion in the scale. The interview should take no more than an hour and will take place at the University of Roehampton or via Skype for participants who are unable to travel to the University of Roehampton.

Each participant will receive a **£10 Amazon voucher** to thank them for their time and participation.

Interview material provided will be treated confidentially and kept in a locked cabinet or on a password protected computer at the University of Roehampton, UK.

If you are interested in taking part in the development of this scale, or would like to find out more, please contact Niamh O' Connor (details below).

This project has been approved under the procedures of the University of Roehampton's Ethics Committee (Ref: 16/237).

If you have any questions regarding this study, please contact Niamh O' Connor, doctoral student, University of Roehampton.

Niamh O' Connor
Department of Psychology
University of Roehampton
Holybourne Avenue
London SW15 4JD
Email: oconnorn@roehampton.ac.uk
Telephone: +44 (0) 7393 709213

TSTI information sheet

University of Roehampton London

INFORMATION SHEET

Interviews for the development of the Diagnosis Impact Scale

This study has been developed by counselling psychology researchers at the University of Roehampton, UK.

The aim of this research is to develop a measure that can assess the impact of mental health diagnosis on those who receive them.

To achieve this, we would be grateful if you could participate in an hour-long interview.

The purpose of these interviews is to hear your responses and views on the scale items, so that we can determine their suitability for inclusion in the scale.

Interviews will take place at the University of Roehampton premises, at an alternative location which is convenient for the participant (suitable for confidential discussion) or via Skype for participants who are unable to travel. They will be audio recorded and take up to an hour. Up to 20 participants will be interviewed.

The interviews consist of three parts: thinking aloud as you fill out the diagnosis impact scale, a focused interview to explore your thoughts further, and lastly an open interview to enquire about your opinion on scale items.

The interview is open to:

-individuals **18 years old or over** who **received a mental health diagnosis six months ago or more**.

Each participant will receive a **£10 Amazon voucher** to thank them for their time and participation.

No one, other than the researchers, will see your individual responses, and they will be treated as entirely anonymous. No names or identifying information will be collected.

The benefit of participating in this research is that you can help to contribute towards the development of a new measure of the impact of mental health diagnosis which will increase the body of knowledge about the experiences of service users. Taking part in the research may be interesting for you in helping you to reflect on your own experience of mental health diagnosis.

The disadvantage of taking part in this study is that there may be a small possibility that thinking about your diagnosis evokes some distressing feelings.

If this occurs, you can alert the Principal Investigator, Niamh O' Connor (carrying out the interviews) who can help you identify the most appropriate source of support. Alternatively, you can contact your GP or a mental health helpline, the contact details for two such helplines are listed below.

MIND

Infoline: 0300 123 3393
Lines are open from 9am to 6pm
Monday to Friday (except bank holidays)

Samaritans

Free Helpline: 116 123
Lines are open 24 hours 7 days per week

There is no payment associated with taking part in this study. You can withdraw from this study at any time without giving a reason, you will not be adversely affected.

This project has been approved under the procedures of the University of Roehampton Ethics Committee (Ref: PSYC 16/237).

Data from this study will be stored in anonymised format for an indefinite period of time. It will be used for one or more journal articles. It may also be used for other educational or teaching purposes, conferences and in additional publications arising from this research. In any publications, your individual responses will not be identifiable in any way.

Please note: if you have a concern about any aspect of your participation or any other queries please raise this with the investigator (or if the researcher is a student you can also contact the Director of Studies:

Principal Investigator Contact Details:
Niamh O' Connor
Department of Psychology
University of Roehampton
Holybourne Avenue
London SW15 4JD
Email: oconnorn@roehampton.ac.uk
mick.cooper@roehampton.ac.uk
Telephone: +44 (0) 7393 709213

Director of Studies Contact Details:
Prof. Mick Cooper
Department of Psychology
University of Roehampton
Holybourne Avenue
London SW15 4JD
Email:

Telephone: 0208 392 3741

However, if you would like to contact an independent party please contact the Head of Department:

Head of Department Contact Details:
Dr. Diane Bray
Department of Psychology
University of Roehampton
Holybourne Avenue
London SW15 4 JD
Email: d.bray@roehampton.ac.uk
Telephone: 0208 392 362

TSTI consent form

PARTICIPANT CONSENT FORM

Interviews for the development of the Diagnosis Impact Scale

Brief Description of Research Project, and What Participation Involves:

In this study we aim to develop a new scale to measure the impact of mental health diagnosis on service users. This part of the scale development involves interviewing up to 20 people who have received a diagnosis six months ago or more to determine the suitability of scale items. Interviews will take place at the University of Roehampton premises, at an alternative location which is convenient for the participant (suitable for confidential discussion) or via Skype for participants who are unable to travel. Interviews are audio recorded and take up to one hour.

Investigator Contact Details:

Niamh O' Connor
Department of Psychology
University of Roehampton
Holybourne Avenue
London SW15 4JD
Email: oconnorn@roehampton.ac.uk
Telephone: +44 (0) 7393 709213

Consent Statement:

I agree to take part in this research, and am aware that I am free to withdraw at any point without giving a reason, although if I do so I understand that my data might still be used in a collated form. I understand that the information I provide will be treated in confidence by the investigator and that my identity will be protected in the publication of any findings, and that data will be collected and processed in accordance with the Data Protection Act 1998 and with the University's Data Protection Policy.

Name ……..

Signature ……

Date ……

If you wish to withdraw from the study, please contact the investigator with the ID number which you will receive on a Debriefing Form after the interview. The data may still be used/ published in an aggregate form.

Please note there is no compulsion to participate. If you heard about this study through a mental health organisation, they will not be informed of your participation or if you withdraw from the study. Therefore, participation or withdrawal from the study **will not** affect your relationship with the organisation or any services you are in receipt of. If you are a student at the University of Roehampton, your grades and relationship with the university will not be affected if you decline to participate in the study or wish to withdraw from participation at any point.

Please note: if you have a concern about any aspect of your participation or any other queries please raise this with the investigator (or if the researcher is a student you can also contact the Director of Studies.) However, if you would like to contact an independent party please contact the Head of Department.

Director of Studies Contact Details:

Prof. Mick Cooper
Department of Psychology
University of Roehampton
Holybourne Avenue
London SW15 4JD
Email: mick.cooper@roehampton.ac.uk
Telephone: 0208 392 3741

Head of Department Contact Details:

Dr. Diane Bray
Department of Psychology
University of Roehampton
Holybourne Avenue
London SW15 4JD
Email: d.bray@roehampton.ac.uk
Telephone: 0208 392 3627

TSTI debriefing form

Interviews for the development of the Diagnosis Impact Scale

Thank you very much for your participation!

ID number:

If you wish to withdraw from the study, please contact the investigator with the ID number which appears above. The data may still be used in an aggregate form.

Please note: if you have a concern about any aspect of your participation or any other queries please raise this with the investigator (or if the researcher is a student you can also contact the Director of Studies

Principal Investigator Contact Details:
Niamh O' Connor
Department of Psychology
University of Roehampton
Holybourne Avenue
London SW15 4JD
Email: oconnorn@roehampton.ac.uk
mick.cooper@roehampton.ac.uk
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However, if you would like to contact an independent party please contact the Head of Department

Head of Department Contact Details:
Dr. Diane Bray
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London SW15 4JD
Email: d.bray@roehampton.ac.uk
Telephone: 0208 392 3627

If you experienced distress while participating in the study please contact the Principal Investigator, your GP or a mental health helpline (contact details for two such helplines are listed below).

MIND

Infoline: 0300 123 3393
Lines are open from 9am to 6pm
Monday to Friday (except bank holidays).

Samaritans

Free Helpline: 116 123
Lines are open 24 hours 7 days per week.

TSTI Analysis and Results

Table 2. TSTI Analysis and Results

Item (issue code)	Action
1. Do you find having a mental health diagnosis (if you have received more than one please answer about the one stated in the previous question)- Very helpful-very unhelpful (1)	Add 'overall/in general'
2. My diagnosis has made me feel I am weak (1)	Change to 'a weak person' due to ambiguity
3. I have felt people looked down on me because of my diagnosis (1)	Change to 'some people' for variety
4. I have felt happier since getting my diagnosis (1)	Change to 'my diagnosis has led to me being happier' for clarity
5. It has felt like people have excused my behaviour because of my diagnosis (1)	Change to 'some people' for variety. Place after social filter question
6. My diagnosis has helped me to access mental health services (1)	Change to 'mental health treatment'
7. People have forced me to have treatment because of my diagnosis (1)	Brackets (medication or any other form of treatment)
8. I have felt my diagnosis means I am 'damaged' (1)	Change to 'a damaged person'
9. My diagnosis has helped me to access specialised care (1)	Change to 'My diagnosis has made me more able to access specialist care'
10. People have seemed overprotective of me because of my diagnosis (1)	Change to 'people close to me'
11. I have felt part of a community because of my diagnosis (1)	Change to 'community of people with the same diagnosis'
12. My diagnosis has given me access to professional help (1)	Change to 'greater access'
13. My diagnosis has made me more dependent on others (3)	Change to 'reliant'
14. It has felt like healthcare professionals do not take me seriously because of my diagnosis (1)	Change to 'take me less seriously'. Add family/friends version?
15. Due to my diagnosis I have been more willing to seek professional help (1)	Change to 'Thanks to'
16. My diagnosis has made me feel my difficulties are taken seriously (1)	Change to 'mental health difficulties'

17. My diagnosis has made me feel I didn't know myself (3)	Change to 'My diagnosis has made me rethink my identity'
18. As a result of my diagnosis I have felt healthcare professionals understand me better (1)	Add 'now'
19. My diagnosis has helped me to feel better (3)	Change to 'about myself'
20. My diagnosis has made me feel labelled (1)	Add 'My diagnosis has made me feel judged'
21. My diagnosis has motivated me to get better (3)	Change to 'find better ways to manage my difficulties'
22. It has felt like people see ordinary things I do as strange because of my diagnosis (2)	Change to 'It has felt like people see normal things I do as strange because of my diagnosis' and 'It has felt like people dismiss things I say because of my diagnosis'
23. It has felt like people view me as dangerous because of my diagnosis	Keep
24. It would have been better if I had not been diagnosed	Keep
25. I have blamed my diagnosis for things that I do	Keep
26. I have been glad I received my diagnosis	Keep
27. My diagnosis has given me more clarity about my difficulties	Keep
28. I have been indifferent to my diagnosis	Keep
29. My diagnosis has made me confused about my difficulties	Keep
30. My diagnosis has been comforting	Keep
31. I wouldn't know who I was without my diagnosis	Keep
32. My diagnosis has made my difficulties worse	Keep
33. My diagnosis has not led to improvements in my mental health difficulties	Keep
34. I have felt I will always be stuck with my diagnosis	Keep
35. I have felt that my diagnosis defines me	Keep
36. My diagnosis has given me hope	Keep
37. I have felt worse about myself because of my diagnosis	Keep
38. My diagnosis has made me feel positive about the future	Keep
39. My diagnosis has helped me to understand myself better	Keep
40. My diagnosis has made me feel like I'm not the only one who feels like I do	Keep
41. Because of my diagnosis, I have been hopeful that I can be helped	Keep

42. My diagnosis has worried me	Keep
43. My diagnosis has made me feel I can be helped	Keep
44. Because of my diagnosis, I have felt my mental health difficulties are someone else's responsibility	Keep
45. I have had less choice in what I do because of my diagnosis	Keep
46. My diagnosis has given me more independence	Keep
47. My diagnosis has helped me to look for information about my difficulties	Keep
48. My diagnosis has made me more willing to ask my family for help	Keep
49. My diagnosis has given me more control over my difficulties	Keep
50. It has felt like people are sympathetic toward me because of my diagnosis	Keep
51. My diagnosis has made me feel safe	Keep
52. My diagnosis has made me feel more 'normal'	Keep
53. My diagnosis has made me think I am crazy	Keep
54. My diagnosis has made me feel special	Keep
55. I have felt ashamed of my diagnosis	Keep
56. Because of my diagnosis, I have not had to work	Keep
57. I have been rejected by people because of my diagnosis	Keep
58. I have felt marginalised because of my diagnosis	Keep
59. People have seemed to treat me like I'm fragile because of my diagnosis	Keep
60. I have felt that healthcare professionals are in control of my life because of my diagnosis	Keep
61. I have felt my diagnosis helps others to understand me	Keep
62. My problems have had more recognition from others because of my diagnosis	Keep
63. My diagnosis has made me feel trapped	Keep
64. It has felt like my friends understand me better because of my diagnosis	Keep
65. My diagnosis has made me feel less alone	Keep
66. It has felt like people expect me to behave a certain way because of my diagnosis	Keep
67. It has felt like my family understand me better because of my diagnosis	Keep

68. My diagnosis has validated my experience	Keep
69. I have had to take medication because of my diagnosis (2)	Remove
70. My diagnosis has made it difficult to get the professional help I wanted (1)	Remove
71. Others have seemed less concerned about me since I received my diagnosis (1)	Remove
72. My life has revolved around my diagnosis (3)	Remove
73. My diagnosis has prevented me from getting more information about my condition from healthcare professionals (1)	Remove
74. I have kept my diagnosis a secret from most people in case they treat me differently (2)	Change to 'I have kept my diagnosis a secret' and 'I have worried that people would treat me differently because of my diagnosis'

1=Ambiguous/general items
2= Double clause items
3= Emotionally-charged language items

Appendix F: Diagnosis Impact Scale- used in online survey for EFA, reliability, and validity analyses

The following is a series of items which relate to the possible impact of having a mental health diagnosis. For the purposes of this study, a mental health 'diagnosis' refers to a specific mental illness label given by a healthcare professional rather than a self-diagnosis or suggestions from friends or loved ones.

Mental illness refers to a wide range of mental health conditions — disorders that affect your mood, thinking, behaviour and overall functioning.

You are asked to think about how your diagnosis has impacted you since you received it, and based on this to indicate your level of agreement with each of the statements.

Whether you received your diagnosis recently or many years ago, you are eligible to complete the survey.

Please bear in mind that the survey is asking about the impact of the diagnosis, itself, on your life, rather than the effect of your mental health difficulties, per se.

If you have received more than one diagnosis, please answer about the diagnosis which has had the greatest effect on you/feels most important to you (this should be the same diagnosis you stated as the most important one earlier in the survey).

The following items are presented (randomised) to all participants:

Emotional 1. It would have been better if I had not been diagnosed

Emotional 2. I have been glad I received my diagnosis

Emotional 3. My diagnosis has given me more clarity about my difficulties

Emotional 4. I have been indifferent to my diagnosis

Emotional 5. My diagnosis has led to me being happier

Emotional 6. My diagnosis has made me confused about my difficulties

Emotional 7. My diagnosis has been comforting

Emotional 8. I have felt I will always be stuck with my diagnosis

Emotional 9. My diagnosis has given me hope

Emotional 10. My diagnosis has made me feel positive about the future

Emotional 11. My diagnosis has worried me

Emotional 12. My diagnosis has validated my experience

Emotional 13. My diagnosis has made me feel my mental health difficulties are taken seriously

Emotional 14. My diagnosis has made me feel safe

Emotional 15. My diagnosis has made me feel labelled

Emotional 16. My diagnosis has made me feel judged

Emotional 17. My diagnosis has made me feel trapped

Identity 1. My diagnosis has made me feel I am a weak person

Identity 2. I wouldn’t know who I was without my diagnosis

Identity 3. I have felt that my diagnosis defines me

Identity 4. I have felt worse about myself because of my diagnosis

Identity 5. I have felt that my diagnosis means I am a 'damaged' person

Identity 6. My diagnosis has helped me to understand myself better

Identity 7. My diagnosis has made me feel like I’m not the only one who feels like I do

Identity 8. Because of my diagnosis I have been hopeful that I can be helped

Identity 9. My diagnosis has made me feel I can be helped

Identity 10. My diagnosis has made me rethink my identity

Identity 11. My diagnosis has made me feel more 'normal'

Identity 12. My diagnosis has made me think I am crazy

Identity 13. My diagnosis has helped me to feel better about myself

Identity 14. My diagnosis has made me feel special

Power 1. I have blamed my diagnosis for things that I do

Power 2. Because of my diagnosis, I have felt my mental health difficulties are someone else's responsibility

Power 3. I have had less choice in what I do because of my diagnosis

Power 4. My diagnosis has made me more reliant on others

Power 5. It has felt like healthcare professionals take me less seriously because of my diagnosis

Power 6. My diagnosis has given me more independence

Power 7. My diagnosis has given me more control over my difficulties

Power 8.I have felt that healthcare professionals are in control of my life because of my diagnosis

Help 1. My diagnosis has made my difficulties worse

Help 2. My diagnosis has not led to improvements in my mental health difficulties

Help 3. My diagnosis has helped me to access mental health treatment

Help 4. People have forced me to have treatment (either medication or any other forms of treatment) because of my diagnosis

Help 5. My diagnosis has made me better able to access specialist care

Help 6. My diagnosis has given me greater access to professional help

Help 7. Thanks to my diagnosis I have been more willing to seek professional help

Help 8. My diagnosis has helped me to look for information about my difficulties

Help 9. As a result of my diagnosis I have felt healthcare professionals understand me better now

Help 10. My diagnosis has motivated me to find better ways of managing my difficulties

Social 1. I have kept my diagnosis a secret from most people

Social 2. I have worried that people would treat me differently if they knew about my diagnosis

Social 3. I have felt part of a community of people with the same/a similar diagnosis

Social 4. I have felt ashamed of my diagnosis

Social 5. I have felt marginalised because of my diagnosis

Social 6. My diagnosis has made me feel less alone

Social Filter: Does anyone in your personal life (i.e. other than healthcare professionals and outside of your employment, education/training) know about your mental health diagnosis? (Response options: Yes/No)

If participants select 'No', they are directed to the 'Employment/Education Filter' item below. Otherwise, they are directed to the following items:

Social 7. People close to me have seemed overprotective of me because of my diagnosis

Social 8. It has felt like my friends have understood me better because of my diagnosis

Social 9. It has felt like people dismiss things I say because of my diagnosis

Social 10. It has felt like people see normal things I do as strange because of my diagnosis

Social 11. It has felt like people view me as dangerous because of my diagnosis

Social 12. It has felt like my family understand me better because of my diagnosis

Social 13. My problems have had more recognition from others because of my diagnosis

Social 14. It has felt like people are sympathetic toward me because of my diagnosis

Social 15. People have seemed to treat me like I'm fragile because of my diagnosis

Social 16. I have felt my diagnosis helps others to understand me

Social 17. I have felt some people looked down on me because of my diagnosis

Social 18. It has felt like people expect me to behave a certain way because of my diagnosis

Social 19. I have felt people rejected me because of my diagnosis

Help 11. My diagnosis has made me more willing to ask my family for help

Help 12. My diagnosis has made me more willing to ask my friends for help

Power 9. It has felt like some people have excused my behaviour because of my diagnosis

Employment/Education Filter: Are you currently employed (work/occupation created from outside the home and involving external people and agencies as opposed to home-making and carer work for children or other family members) or in education/training? If so, please specify below (Response options: Employed/In education or training/Both/Neither)

If participants select 'Neither' they are directed to:

Employment/Education Reason: Do you feel you have been unable to secure employment or access education/training due to your diagnosis? (Response options: Yes/No/I don't know)

Otherwise, they are directed to the employment items, education items, or both, as applicable.

Employment 1. My diagnosis has had a negative effect on my career

Employment 2. I have felt my diagnosis makes it more difficult to get a job

Employment 3. I have felt I am less likely to be promoted at work because of my diagnosis

Employment 4. It has felt like people view me differently from others at work because of my diagnosis

Employment 5. My diagnosis has helped me to get time off work

Employment 6. My diagnosis has led to being treated better at work

Education 1. My diagnosis has made it more difficult to access education/training

Education 2. My diagnosis has meant that I can take breaks from education/training when I need to

Education 3. My diagnosis has meant that changes are made to facilitate me in education/training

Education 4. I have felt people are reluctant to do group exercises/projects with me because of my diagnosis

Education 5. I have felt people view me differently to others on my course because of my diagnosis

Appendix G: Main Survey Recruitment, Information Sheet, Consent Form, Demographics Items, Validity Scales, and Debriefing Form

Participant recruitment email

Hello,

I am a trainee counselling psychologist at the University of Roehampton. Along with my supervisors, Prof Mick Cooper and Dr Gina Pauli, I am conducting a study which I thought your service might be interested in.

The study invites participants to reflect on their mental health diagnosis and how it has affected their lives which can be quite a therapeutic and validating experience. Below is a brief outline of the research and I have attached a participant information sheet for further details.

At CREST (Centre for Research in Social and Psychological Transformation, University of Roehampton, Director: Prof Mick Cooper), we are looking to develop a self-report measure of the impact of mental health diagnoses on those who receive them.

Our aim is that the measure can be used for both clinical and research purposes. Clinically, it is hoped that the use of this scale will empower people who receive diagnoses and encourage a dialogue with professionals on the experience of receiving and having them. Research-wise, we are hoping to use the measure to explore predictors of the impact of diagnosis: for example, gender, time since diagnosis, and 'type' of diagnosis.

To progress this research, we are looking for non-NHS practitioners and services that would be willing to help with the recruitment of participants (anyone 18 or over who has received a mental health diagnosis from a healthcare professional) who will be asked to complete a short online survey. This help could be by **sending email invites (see below) to staff and service users, adding a link to the survey on a website/social media page, and/or allowing recruitment posters to be displayed in branches of a service.**

If you are interested at all in helping us, please reply to this email or contact me at oconnorn@roehampton.ac.uk to discuss this further.

Warm regards,

Niamh O' Connor

Dear service user/staff member,

We are forwarding on an email to you regarding a survey that you may be interested in participating in.

At CREST (Centre for Research in Social and Psychological Transformation, University of Roehampton, Director: Prof Mick Cooper), we are developing a self-report measure of the impact of mental health diagnoses on those who receive them.

Our aim is that the measure can be used for both clinical and research purposes. Clinically, it is hoped that the use of this scale will empower people who receive diagnoses and encourage a dialogue with professionals on the experience of receiving and having them. Research-wise, we are hoping to use the measure to explore predictors of the impact of diagnosis: for example, gender, time since diagnosis, and 'type' of diagnosis.

To progress this research, we are looking for **anyone aged 18 or over who has received a mental health diagnosis** to participate in a short online survey. It should not take longer than 20 minutes and is completely anonymous, names and IP addresses are not collected. If you are interested in taking part in this survey, or would like to find out more, please click the link below.

https://roehamptonpsych.az1.qualtrics.com/jfe/form/SV_8idTrY4v22U3nhj

This project has been approved under the procedures of the University of Roehampton's Ethics Committee (Ref: PSYC 16/237).

If you have any questions regarding this study, please contact Niamh O' Connor, doctoral student, University of Roehampton.

Niamh O' Connor
Department of Psychology
University of Roehampton
Holybourne Avenue
London SW15 4JD
Email: oconnorn@roehampton.ac.uk
Telephone: +44 (0) 7393 709213

Main survey participant recruitment social media post

DEVELOPING A MEASURE TO ASSESS THE IMPACT OF MENTAL HEALTH DIAGNOSIS

At CREST (Centre for Research in Social and Psychological Transformation, University of Roehampton, Director: Mick Cooper), we are looking to develop a self-report measure of the impact of a mental health diagnoses on those who receive them.

Our aim is that the measure can be used for both clinical and research purposes. Clinically, it is hoped that the use of this scale will empower people with a mental health diagnosis and encourage a dialogue with professionals on the experience of receiving and having a mental health diagnosis. Research-wise, we are hoping to use the measure to explore predictors of the impact of diagnosis: for example, gender, time since diagnosis, and 'type' of diagnosis.

To progress this research, **we are looking for people aged 18 or over who have received a mental health diagnosis from a healthcare professional** to complete a short online survey. If you are interested in participating please follow the link below:

https://roehamptonpsych.az1.qualtrics.com/jfe/form/SV_8idTrY4v22U3nhj

If you have any questions about the study, please contact Niamh at oconnorn@roehampton.ac.uk

Main survey information sheet

INFORMATION SHEET

Diagnosis Impact Scale development study

This study has been developed by counselling psychology researchers at the University of Roehampton, UK.

The aim of this research is to develop a measure that can assess the impact of mental health diagnosis on those who receive them.

To achieve this, we would be grateful if you could complete a short survey. It should take no more than 20 minutes.

The survey is open to:

-individuals **18 years old or over** who have **received a mental health diagnosis from a healthcare professional**.

What participation involves:

When you click the survey link you will first be asked to agree to an informed consent statement. The survey asks you some basic demographic questions. It then asks you about aspects of mental health diagnosis and their effect on you, after which you will be presented with some more short questionnaires. These are included for statistical validation purposes.

No one, other than the researchers, will see your individual responses, and they will be treated as entirely anonymous. No names or identifying information will be collected.

The benefit of participating in this research is that you can help to contribute towards the development of a new measure of the impact of mental health diagnosis which will increase the body of knowledge about the experiences of service users. Taking part in the research may be interesting for you in helping you to reflect on your own experience of mental health diagnosis.

The disadvantage of taking part in this study is that there may be a small possibility that thinking about your diagnosis evokes some distressing feelings.

If this occurs, you can contact the Principal Investigator of the study, Niamh O' Connor (contact details below), who can help you identify the most appropriate source of support. Alternatively, you can contact you GP or a mental health helpline, the contact details for two such helplines are listed below.

MIND

Infoline: 0300 123 3393
Lines are open from 9am to 6pm
Monday to Friday (except bank holidays)

Samaritans

Free Helpline: 116 123
Lines are open 24 hours 7 days per week

You are advised to **PRINT** this information sheet before starting the survey in case you experience distress during while participating.

The questions in this survey are of a sensitive nature and participants are asked to assess whether they feel they are in the right state of mind to answer items relating to their diagnosis.

If you have already participated in an earlier phase of the research, we are very grateful for your continued interest but unfortunately for technical reasons we can only allow participation in one part of the study.

There is no payment associated with taking part in this study.

You can withdraw from this study at any time by simply exiting the survey.

This project has been approved under the procedures of the University of Roehampton Ethics Committee (Ref: PSYC 16/237).

Data from this study will be stored in an anonymised format for an indefinite period of time. It will be used for one or more journal articles and may also be used for other educational or teaching purposes, conferences and in additional publications arising from this research. In any publications, your individual responses will not be identifiable in any way.

Please note: if you have a concern about any aspect of your participation or any other queries please raise this with the investigator (or if the researcher is a student you can also contact the Director of Studies)

Principal Investigator Contact Details:
Niamh O' Connor
Department of Psychology
University of Roehampton
Holybourne Avenue
London SW15 4JD
Email: oconnorn@roehampton.ac.uk
Telephone: +44 (0) 7393 709213

Director of Studies Contact Details:
Prof. Mick Cooper
Department of Psychology
University of Roehampton
Holybourne Avenue
London SW15 4JD
Email: mick.cooper@roehampton.ac.uk
Telephone: +44 (0) 208 392 3741

However, if you would like to contact an independent party please contact the Head of Department:

Head of Department Contact Details:
Dr. Diane Bray
Department of Psychology
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Main survey consent form

PARTICIPANT CONSENT FORM

Diagnosis Impact Scale Development Survey

In this study we aim to develop a new scale to measure the impact of mental health diagnoses on those who receive them. Questionnaires will take up to 20 minutes to complete and will include questions on different aspects of receiving and having a mental health diagnosis and any effects of these. We are hoping to reach 300 responses to the survey.

Investigator Contact Details:

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Consent Statement:

I am 18 or over and I agree to take part in this research I am aware that I am free to withdraw at any point without giving a reason, although if I do so I understand that my data might still be used in a collated form. I understand that the information I provide will be treated in confidence by the investigator and that my identity will be protected in the publication of any findings, and that data will be collected and processed in accordance with the General Data Protection Regulation and Data Protection Act 2018 and with the University's Data Protection Policy.

- Yes
- No

If you wish to withdraw from the study, please contact the investigator with the ID number which you will generate at the beginning of the survey. The data may still be used/ published in an aggregate form.

Please note there is no compulsion to participate. If you heard about this study through a mental health organisation, they will not be informed of your participation or if you withdraw from the study. Therefore, participation or withdrawal from the study will not affect your relationship with the organisation or any services you are in receipt of. If you are a student at the University of Roehampton, your grades and relationship with the university will not be affected if you decline to participate in the study or wish to withdraw from participation at any point.

Please note: if you have a concern about any aspect of your participation or any other queries please raise this with the investigator (or if the researcher is a student you can also contact the Director of

Studies.) However, if you would like to contact an independent party please contact the Head of Department.

Director of Studies Contact Details:

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Main survey debriefing form

Thank you very much for your participation!!

ID number:

If you wish to withdraw from the study, please contact the investigator with the ID number which appears above. The data may still be used in an aggregate form.

Please note: if you have a concern about any aspect of your participation or any other queries please raise this with the investigator (or if the researcher is a student you can also contact the Director of Studies). However, if you would like to contact an independent party please contact the Head of Department.

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If you experienced distress while participating in the study please contact the Principal Investigator, your GP or a mental health helpline (contact details for two such helplines are listed below).

Mind
Infoline: 0300 123 3393
Lines are open 9am to 6pm Monday to Friday (except bank holidays).

Samaritans

Free Helpline: 116 123
Lines are open 24 hours 7 days per week.

Appendix H: DIS Item Counts by Scale Development Stage

Table 3. DIS item counts by scale development stage

Stage	Demographics	Total Items	Main Scale Items	Social Impact Items	Employment Impact Items	Education Impact Items
Online rating	4	109	97	Included in Main Scale	7	5
TSTI	13	85	74	Included in Main Scale	6	5
Pilot main survey	17	82	55 (including 6 social impact items)	'Others know' branch includes 13 social impact items, 2 help subscale items and 1 power subscale item. There were 16 items in total.	6	5
Main survey	17	82	As above	As above	6	5
2 Dimensional scale after EFA		19	19	0	0	0

Appendix I: Criterion Validity and Socio-Demographic Items

1. Have you been diagnosed with a mental health disorder by a healthcare professional in the past?

2. What was the diagnosis? Please state the diagnosis (if you have received more than one please state the one which holds most importance for you)
3. Who did you received the diagnosis from?
    - Psychiatrist
    - Counsellor
    - General Practitioners (GP)
    - Mental health nurse
    - Psychologist
    - Psychotherapist
    - CBT therapist
    - Psychoanalyst
    - Family therapist
    - Couples therapist
    - Other- please specify
    - I don't know
4. How long ago (approximately) did you receive the diagnosis? Please state the number of years and months or if it has been less than a year please use the 'Months' space. If you do not remember when you received the diagnosis please type 'Don't know' in both spaces.
    - Years
    - Months
5. Overall, have you found having a mental health diagnosis (if you have received more than one please answer about the one stated in the previous question)
    - Very helpful?
    - Helpful?
    - Neither helpful nor unhelpful?
    - Unhelpful?
    - Very unhelpful?
6. Have you received more than one mental health diagnosis?
    - Yes
    - No
    - I don't know
7. If you answered 'Yes' to the previous question, how many different diagnoses have you received?
8. Do you feel you have received the correct diagnosis?
    - Yes
    - No
    - I don't know
9. Are you currently receiving treatment because of your diagnosis?
    - Yes
    - No
    - I don't know
10. Do you find this treatment helpful in managing your mental health difficulties?
11. If you are currently in employment or education/training, have you had formal assistance/allowances put in place by your employer or education/training provider because of your diagnosis? If you are not currently in employment, education or training, please select 'Not applicable'
    - Yes
    - No
    - I don't know
    - Not applicable
12. What is your gender?

- Male
- Female
- Other

13. What is your age?
14. Please select your ethnicity
    - White British
    - White Irish
    - White Other Background
    - White and Black Caribbean
    - White and Black African
    - Mixed White and Asian
    - Other Mixed Background
    - Indian
    - Pakistani
    - Bangladeshi
    - Other Asian Background
    - Caribbean
    - African
    - Other Black Background
    - Chinese or Chinese British
    - Other Ethnic Background
15. In what country do you currently live?
16. What is your occupation?
17. Are you a mental health professional (e.g. psychotherapist, counsellor, psychologist, psychiatrist, mental health nurse etc.) either in training or qualified?
    - Yes
    - No
18. How did you hear about this study? If it was through an organisation (including social media pages or websites) please specify which organisation.

Appendix J: Patient Feedback on Consultation Skills Questionnaire (PFC)

Please answer the following with reference to the communication of your diagnosis. If you have received more than one mental health diagnosis please answer the following questionnaire on the one which you stated at the beginning of this survey.

1. To what extent was your problem (s) discussed?
    - Completely
    - Mostly
    - A little
    - Not at all
2. How satisfied were you with the discussion of your problem?
    - Completely
    - Mostly
    - A little
    - Not at all

To what extent did:

3. the healthcare professional listen to what you had to say?
    - Completely
    - Mostly
    - A little
    - Not at all
4. the healthcare professional explain this problem to you?
    - Completely
    - Mostly
    - A little
    - Not at all
5. you and the healthcare professional discuss your respective roles?
    - Completely
    - Mostly
    - A little
    - Not at all
6. the healthcare professional explain treatment?

To what extent did:

7. the healthcare professional explore how manageable this treatment would be for you?
    - Completely
    - Mostly
    - A little
    - Not at all
8. How well do you think your healthcare professional understood you?
    - Completely
    - Mostly
    - A little
    - Not at all

To what extent

9. did the healthcare professional discuss personal or family issues that might affect your health?
    - Completely
    - Mostly
    - A little
    - Not at all
10. Was there an atmosphere of trust during the consultation?

- Completely
- Mostly
- A little
- Not at all

To what extent did:

11. the healthcare professional show his/her concern?
    - Completely
    - Mostly
    - A little
    - Not at all
12. the healthcare professional invite you to ask all the questions you wanted to ask?
    - Completely
    - Mostly
    - A little
    - Not at all
13. the healthcare professional give you clear information and explanation?
    - Completely
    - Mostly
    - A little
    - Not at all
14. the healthcare professional act in a structured way?
    - Completely
    - Mostly
    - A little
    - Not at all

To what extent did:

15. the healthcare professional give you new or better insight into your problem?
    - Completely
    - Mostly
    - A little
    - Not at all
16. the healthcare professional give you clear treatment advice?
    - Completely
    - Mostly
    - A little
    - Not at all

Reinders, Marcel E., Blankenstein, Annette H., Knol, Dirk L., de Vet, Henrica C. W., & van Marwijk, Harm W. J. (2009). Validity aspects of the patient feedback questionnaire on consultation skills (PFC), a promising learning instrument in medical education. Patient Education and Counseling, Vol 76(2), 202-206. doi: 10.1016/j.pec.2009.02.003, © 2009 by Elsevier

Appendix K: Satisfaction with Life Scale (SWLS)

Below are five statements that you may agree or disagree with. Using the 1-7 scale below, indicate your agreement with each item by selecting the appropriate number. Please be open and honest in your responding.

7- Strongly agree

6- Agree

5- Slightly agree

4- Neither agree nor disagree

3- Slightly disagree

2- Disagree

1- Strongly disagree

In most ways my life is close to my ideal

7- Strongly agree

6- Agree

5- Slightly agree

4- Neither agree nor disagree

3- Slightly disagree

2- Disagree

1- Strongly disagree

The conditions of my life are excellent

7- Strongly agree

6- Agree

5- Slightly agree

4- Neither agree nor disagree

3- Slightly disagree

2- Disagree

1- Strongly disagree

I am satisfied with my life

7- Strongly agree

6- Agree

5- Slightly agree

4- Neither agree nor disagree

3- Slightly disagree

2- Disagree

1- Strongly disagree

So far I have gotten the important things I want in life

7- Strongly agree

6- Agree

5- Slightly agree

4- Neither agree nor disagree

3- Slightly disagree

2- Disagree

1- Strongly disagree

If I could live my life over, I would change almost nothing

7- Strongly agree

6- Agree

5- Slightly agree

4- Neither agree nor disagree

3- Slightly disagree

2- Disagree

1- Strongly disagree

Appendix L: Social Desirability Scale-17 (SDS-17)

Instructions

Below you will find a list of statements. Please read each statement carefully and decide if that statement describes you or not. If it describes you, check the word "true"; if not, check the word "false".

1. I sometimes litter.
    - True
    - False
2. I always admit my mistakes openly and face the potential negative consequences.
    - True
    - False
3. In traffic I am always polite and considerate of others.
    - True
    - False
4. I have tried illegal drugs (for example, marijuana, cocaine, etc.)
    - True
    - False
5. I always accept others' opinions, even when they don't agree with my own.
    - True
    - False
6. I take out my bad moods on others now and then.
    - True
    - False
7. There has been an occasion when I took advantage of someone else.
    - True
    - False
8. In conversations I always listen attentively and let others finish their sentences.
    - True
    - False
9. I never hesitate to help someone in case of emergency.
    - True
    - False
10. When I have made a promise, I keep it - no ifs, ands, or buts.
    - True
    - False
11. I occasionally speak badly of others behind their back.
    - True
    - False
12. I would never live off other people.
    - True
    - False
13. I always stay friendly and courteous with other people, even when I am stressed out.
    - True
    - False
14. During arguments I always stay objective and matter-of-fact.
    - True
    - False
15. There has been at least one occasion when I failed to return an item that I borrowed.
    - True
    - False
16. I always eat a healthy diet.
    - True
    - False

17. Sometimes I only help because I expect something in return.
    - True
    - False

Appendix M: CORE-10

IMPORTANT – PLEASE READ THIS FIRST

This form has 10 statements about how you have been OVER THE LAST WEEK. Please read each statement and think how often you felt that way last week. Then tick the box which is closest to this.

Over the last week

1. I have felt tense, anxious or nervous
    - Not at all
    - Only occasionally
    - Sometimes
    - Often
    - Most or all of the time
2. I have felt I have someone to turn to for support when needed
    - Not at all
    - Only occasionally
    - Sometimes
    - Often
    - Most or all of the time
3. I have felt able to cope when things go wrong
    - Not at all
    - Only occasionally
    - Sometimes
    - Often
    - Most or all of the time
4. Talking to people has felt too much for me
    - Not at all
    - Only occasionally
    - Sometimes
    - Often
    - Most or all of the time
5. I have felt panic or terror
    - Not at all
    - Only occasionally
    - Sometimes
    - Often
    - Most or all of the time
6. I made plans to end my life
    - Not at all
    - Only occasionally
    - Sometimes
    - Often
    - Most or all of the time
7. I have had difficulty getting to sleep or staying asleep
    - Not at all
    - Only occasionally
    - Sometimes
    - Often
    - Most or all of the time
8. I have felt despairing or hopeless
    - Not at all
    - Only occasionally

- Sometimes
- Often
- Most or all of the time

9. I have felt unhappy
    - Not at all
    - Only occasionally
    - Sometimes
    - Often
    - Most or all of the time
10. Unwanted images or memories have been distressing me
    - Not at all
    - Only occasionally
    - Sometimes
    - Often
    - Most or all of the time

Appendix N: Positive and Negative Affect Schedule (PANAS)

This scale consists of a number of words that describe different feelings and emotions. Read each item and then mark the appropriate answer in the space next to that word. Indicate to what

extent you have felt this way during the past week. Use the following scale to record your answers.

1- Very slightly or not at all

2- A little

3- Moderately

4- Quite a bit

5- Extremely

Interested

1- Very slightly or not at all

2- A little

3- Moderately

4- Quite a bit

5- Extremely

Distressed

1- Very slightly or not at all

2- A little

3- Moderately

4- Quite a bit

5- Extremely

Excited

1- Very slightly or not at all

2- A little

3- Moderately

4- Quite a bit

5- Extremely

Upset

1- Very slightly or not at all

2- A little

3- Moderately

4- Quite a bit

5- Extremely

Strong

1- Very slightly or not at all

2- A little

3- Moderately

4- Quite a bit

5- Extremely

Guilty

1- Very slightly or not at all

2- A little

3- Moderately

4- Quite a bit

5- Extremely

Scared

1- Very slightly or not at all

2- A little

3- Moderately

4- Quite a bit

5- Extremely

Hostile

1- Very slightly or not at all

2- A little

3- Moderately

4- Quite a bit

5- Extremely

Enthusiastic

1- Very slightly or not at all

2- A little

3- Moderately

4- Quite a bit

5- Extremely

Proud

1- Very slightly or not at all

2- A little

3- Moderately

4- Quite a bit

5- Extremely

Irritable

1- Very slightly or not at all

2- A little

3- Moderately

4- Quite a bit

5- Extremely

Alert

1- Very slightly or not at all

2- A little

3- Moderately

4- Quite a bit

5- Extremely

Ashamed

1- Very slightly or not at all

2- A little

3- Moderately

4- Quite a bit

5- Extremely

Inspired

1- Very slightly or not at all

2- A little

3- Moderately

4- Quite a bit

5- Extremely

Nervous

1- Very slightly or not at all

2- A little

3- Moderately

4- Quite a bit

5- Extremely

Determined

1- Very slightly or not at all

2- A little

3- Moderately

4- Quite a bit

5- Extremely

Attentive

1- Very slightly or not at all

2- A little

3- Moderately

4- Quite a bit

5- Extremely

Jittery

1- Very slightly or not at all

2- A little

3- Moderately

4- Quite a bit

5- Extremely

Active

1- Very slightly or not at all

2- A little

3- Moderately

4- Quite a bit

5- Extremely

Afraid

1- Very slightly or not at all

2- A little

3- Moderately

4- Quite a bit

5- Extremely

Watson, David, Clark, Lee Anna, & Tellegen, Auke. (1988). Development and validation of brief measures of positive and negative affect: The PANAS scales. Journal of Personality and Social Psychology, Vol 54(6), 1063-1070. doi: 10.1037/0022-3514.54.6.1063

Appendix O: Changes to Online Psychometric Study Survey after Posting on Qualtrics

Table 4. Changes to online psychometric study survey during data collection

Survey Section	Item	Amendment
Information sheet	N/A	Addition of 'If you have already participated in an earlier phase of the research, we are very grateful for your continued interest but unfortunately for technical reasons we can only allow participation in one part of the study.'
Consent form	N/A	In the consent statement, the reference to the Data Protection Act was updated and General Data Protection Regulations was added.
Demographics	Who did you receive the diagnosis from?	'I don't know' response option added.
Demographics	Overall, have you found having a mental health diagnosis (if you have received more than one please answer about the one stated in the previous question) Very helpful? Helpful? Neither helpful nor unhelpful? Unhelpful? Very unhelpful?	'I don't know' response option added.
Demographics	Have you received more than one mental health diagnosis?	'I don't know' response option added.
Demographics	Do you feel you have received the correct diagnosis?	'I don't know' response option added.
Demographics	Are you currently receiving treatment because of your diagnosis?	'I don't know' response option added.

Demographics	If you are currently in employment or education/training, have you had formal assistance/allowances put in place by your employer or education/training provider because of your diagnosis? If you are not currently in employment, education or training please select N/A	'I don't know' response option added.
Demographics	What is your gender?	'Other' response option with text entry box added.
Introduction	N/A	Examples of mental illnesses removed.

Appendix P: DIS Item Descriptive Statistics

DIS Main Scale Item Means, Standard Deviations, Skewness, and Kurtosis

Item	Mean	Standard Deviation	Skewness	Kurtosis

Emotional 1. It would have been better if I had not been diagnosed	3.87	1.43	-0.90	-0.65
Emotional 2. I have been glad I received my diagnosis	3.51	1.42	-0.65	-0.88
Emotional 3. My diagnosis has given me more clarity about my difficulties	3.68	1.28	-0.90	-0.27
Emotional 4. I have been indifferent to my diagnosis	2.26	1.17	0.48	-0.90
Emotional 5. My diagnosis has led to me being happier	2.76	1.35	0.04	-1.26
Emotional 6. My diagnosis has made me confused about my difficulties	2.55	1.36	0.35	-1.22
Emotional 7. My diagnosis has been comforting	2.84	1.31	-0.12	-1.31
Emotional 8. I have felt I will always be stuck with my diagnosis	3.58	1.39	-0.70	-0.82
Emotional 9. My diagnosis has given me hope	2.75	1.29	0.02	-1.16
Emotional 10. My diagnosis has made me feel positive about the future	2.50	1.22	0.26	-0.98
Emotional 11. My diagnosis has worried me	3.68	1.25	-0.90	-0.22
Emotional 12. My diagnosis has validated my experience	3.55	1.35	-0.72	-0.66
Emotional 13. My diagnosis has made me feel my mental health difficulties are taken seriously	3.41	1.32	-0.59	-0.83
Emotional 14. My diagnosis has made me feel safe	2.30	1.12	0.39	-0.77
Emotional 15. My diagnosis has made me feel labelled	3.31	1.41	-0.38	-1.14
Emotional 16. My diagnosis has made me feel judged	3.42	1.38	-0.47	-1.12
Emotional 17. My diagnosis has made me feel trapped	3.04	1.48	-0.09	-1.47
Identity 1. My diagnosis has made me feel I am a weak person	2.94	1.46	-0.09	-1.45
Identity 2. I wouldn’t know who I was without my diagnosis	2.01	1.24	0.88	-0.52

Identity 3. I have felt that my diagnosis defines me	2.68	1.39	0.11	-1.41
Identity 4. I have felt worse about myself because of my diagnosis	2.96	1.40	-0.03	-1.30
Identity 5. I have felt that my diagnosis means I am a 'damaged' person	3.33	1.41	-0.54	-1.09
Identity 6. My diagnosis has helped me to understand myself better	3.68	1.24	-0.89	-0.11
Identity 7. My diagnosis has made me feel like I’m not the only one who feels like I do	3.73	1.23	-1.00	0.09
Identity 8. Because of my diagnosis I have been hopeful that I can be helped	3.33	1.32	-0.58	-0.87
Identity 9. My diagnosis has made me feel I can be helped	3.34	1.33	-0.58	-0.90
Identity 10. My diagnosis has made me rethink my identity	3.43	1.34	-0.61	-0.88
Identity 11. My diagnosis has made me feel more 'normal'	2.54	1.28	0.22	-1.21
Identity 12. My diagnosis has made me think I am crazy	2.65	1.45	0.23	-1.40
Identity 13. My diagnosis has helped me to feel better about myself	2.72	1.33	0.06	-1.26
Identity 14. My diagnosis has made me feel special	1.78	1.05	1.02	-0.30
Power 1. I have blamed my diagnosis for things that I do	3.07	1.36	-0.38	-1.25
Power 2. Because of my diagnosis, I have felt my mental health difficulties are someone else's responsibility	1.55	0.95	1.76	2.38
Power 3. I have had less choice in what I do because of my diagnosis	2.67	1.49	0.27	-1.42
Power 4. My diagnosis has made me more reliant on others	2.55	1.34	0.23	-1.32
Power 5. It has felt like healthcare professionals take me less seriously because of my diagnosis	2.82	1.49	0.10	-1.47

Power 6. My diagnosis has given me more independence	2.45	1.19	0.27	-0.92
Power 7. My diagnosis has given me more control over my difficulties	3.16	1.32	-0.42	-1.02
Power 8. I have felt that healthcare professionals are in control of my life because of my diagnosis	2.29	1.41	0.62	-1.07
Power 9. It has felt like some people have excused my behaviour because of my diagnosis	2.63	1.24	0.03	-1.28
Help 1. My diagnosis has made my difficulties worse	3.64	1.33	-0.61	-0.84
Help 2. My diagnosis has not led to improvements in my mental health difficulties	2.84	1.52	0.10	-1.50
Help 3. My diagnosis has helped me to access mental health treatment	3.54	1.44	-0.73	-0.88
Help 4. People have forced me to have treatment (either medication or any other forms of treatment) because of my diagnosis	2.68	1.58	0.24	-1.56
Help 5. My diagnosis has made me better able to access specialist care	3.17	1.45	-0.34	-1.28
Help 6. My diagnosis has given me greater access to professional help	3.34	1.46	-0.49	-1.18
Help 7. Thanks to my diagnosis I have been more willing to seek professional help	3.52	1.30	-0.75	-0.53
Help 8. My diagnosis has helped me to look for information about my difficulties	4.11	1.04	-1.51	2.10
Help 9. As a result of my diagnosis I have felt healthcare professionals understand me better now	2.90	1.37	-0.16	-1.35
Help 10. My diagnosis has motivated me to find better ways of managing my difficulties	3.73	1.23	-0.94	-0.05

Help 11. My diagnosis has made me more willing to ask my family for help	2.80	1.40	-0.01	-1.43
Help 12. My diagnosis has made me more willing to ask my friends for help	2.87	1.36	-0.13	-1.35

DIS Social Impact Scale Means, Standard Deviations, Skewness, and Kurtosis

Item	Mean	Standard Deviation	Skewness	Kurtosis
Social 1. I have kept my diagnosis a secret from most people	3.45	1.48	-0.49	-1.21
Social 2. I have worried that people would treat me differently if they knew about my diagnosis	4.11	1.06	-1.36	1.29
Social 3. I have felt part of a community of people with the same/a similar diagnosis	2.64	1.32	0.14	-1.30
Social 4. I have felt ashamed of my diagnosis	3.42	1.47	-0.54	-1.16
Social 5. I have felt marginalised because of my diagnosis	3.14	1.43	-0.14	-1.29
Social 6. My diagnosis has made me feel less alone	2.86	1.29	-0.21	-1.31
Social 7. People close to me have seemed overprotective of me because of my diagnosis	2.86	1.36	-0.06	-1.31
Social 8. It has felt like my friends have understood me better because of my diagnosis	3.06	1.27	-0.34	-1.09
Social 9. It has felt like people dismiss things I say because of my diagnosis	3.03	1.49	-0.09	-1.45
Social 10. It has felt like people see normal things I do as strange because of my diagnosis	3.01	1.40	-0.22	-1.28
Social 11. It has felt like people view me as dangerous because of my diagnosis	2.36	1.59	0.56	-1.32

Social 12. It has felt like my family understand me better because of my diagnosis	2.91	1.41	-0.17	-1.45
Social 13. My problems have had more recognition from others because of my diagnosis	3.02	1.29	-0.23	-1.11
Social 14. It has felt like people are sympathetic toward me because of my diagnosis	2.90	1.27	-0.17	-1.11
Social 15. People have seemed to treat me like I'm fragile because of my diagnosis	3.04	1.32	-0.23	-1.19
Social 16. I have felt my diagnosis helps others to understand me	2.91	1.36	-0.17	-1.36
Social 17. I have felt some people looked down on me because of my diagnosis	3.34	1.42	-0.38	-1.18
Social 18. It has felt like people expect me to behave a certain way because of my diagnosis	3.27	1.33	-0.39	-1.03
Social 19. I have felt people rejected me because of my diagnosis	2.83	1.49	0.17	-1.43

DIS Employment Impact Scale Item Means, Standard Deviations, Skewness, and Kurtosis

Item	Mean	Standard Deviation	Skewness	Kurtosis
Employment 1. My diagnosis has had a negative effect on my career	3.12	1.49	-0.18	-1.42
Employment 2. I have felt my diagnosis makes it more difficult to get a job	3.10	1.50	-0.17	-1.44
Employment 3. I have felt I am less likely to be promoted at work because of my diagnosis	2.85	1.43	0.07	-1.34
Employment 4. It has felt like people view me differently from others at work because of my diagnosis	2.99	1.41	-0.11	-1.27

Employment 5. My diagnosis has helped me to get time off work	2.76	1.48	0.05	-1.47
Employment 6. My diagnosis has led to being treated better at work	2.43	1.24	0.29	-0.99

DIS Educational Impact Scale Item Means, Standard Deviations, Skewness, and Kurtosis

Item	Mean	Standard Deviation	Skewness	Kurtosis
Education 1. My diagnosis has made it more difficult to access education/training	2.55	1.42	0.43	-1.15
Education 2. My diagnosis has meant that I can take breaks from education/training when I need to	2.99	1.28	-0.12	-1.19
Education 3. My diagnosis has meant that changes are made to facilitate me in education/training	2.95	1.36	-0.03	-1.22
Education 4. I have felt people are reluctant to do group exercises/projects with me because of my diagnosis	2.29	1.37	0.59	-0.99
Education 5. I have felt people view me differently to others on my course because of my diagnosis	2.84	1.39	0.06	-1.23

Appendix Q: Exploratory Factor Analysis Scree Plot

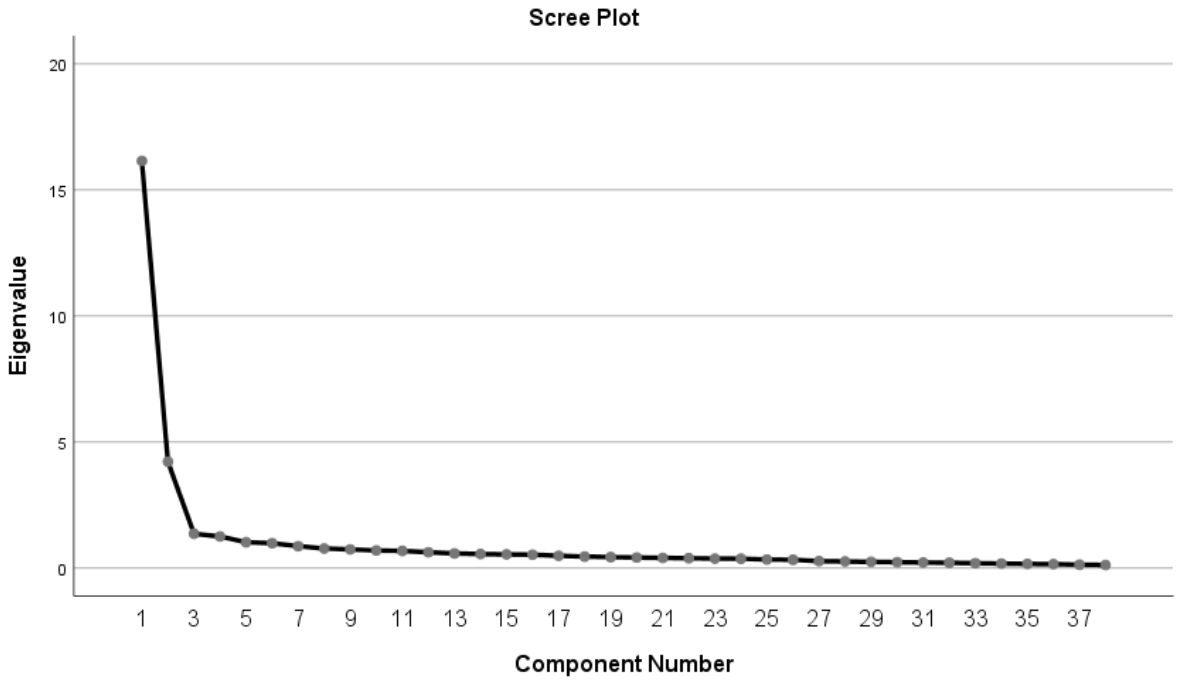

Figure X. Scree Plot

Appendix R: Helpfulness of Diagnosis and Diagnosis-Related Self-Stigma Item Total Correlations and Cronbach's Alpha if Item Deleted

Item Total Correlations and Cronbach's Alpha of Helpfulness of Diagnosis Subscale

Item	Corrected Item-Total Correlation	Cronbach's Alpha if Item
It would have been better if I had not been diagnosed	.806	.923
My diagnosis has led to me being happier	.769	.925
My diagnosis has been comforting	.707	.927
My diagnosis has given me hope	.736	.926
My diagnosis has made me feel my mental health difficulties are taken seriously	.681	.928
My diagnosis has helped me to understand myself better	.764	.925
My diagnosis has made me feel more 'normal'	.645	.930
My diagnosis has helped me to feel better about myself	.784	.924
My diagnosis has made my difficulties worse	.720	.927
My diagnosis has given me greater access to professional help	.569	.933
My diagnosis has motivated me to find better ways of managing my difficulties	.600	.931
Thanks to my diagnosis I have been more willing to seek professional help	.706	.927

Item Total Correlations and Cronbach's Alpha of Self-Stigma Subscale

Item	Corrected Item-Total Correlation	Cronbach's Alpha if Item Deleted
My diagnosis has made me feel I am a weak person	.655	.771
I have felt I will always be stuck with my diagnosis	.542	.792
I have felt that my diagnosis defines me	.581	.785
I have felt that my diagnosis means I am a 'damaged' person	.635	.775
My diagnosis has made me more reliant on others	.405	.814
My diagnosis has made me rethink my identity	.442	.808
My diagnosis has made me think I am crazy	.604	.781

Appendix S: Final Diagnosis Impact Scale Items

Helpfulness of Diagnosis Items:

It would have been better if I had not been diagnosed

My diagnosis has led to me being happier

My diagnosis has been comforting

My diagnosis has given me hope

My diagnosis has made me feel my mental health difficulties are taken seriously

My diagnosis has helped me to understand myself better

My diagnosis has made me feel more 'normal'

My diagnosis has helped me to feel better about myself

My diagnosis has made my difficulties worse

My diagnosis has given me greater access to professional help

Thanks to my diagnosis I have been more willing to seek professional help

My diagnosis has motivated me to find better ways of managing my difficulties

Diagnosis-Related Self-Stigma Items:

My diagnosis has made me feel I am a weak person

I have felt that my diagnosis defines me

I have felt that my diagnosis means I am a 'damaged' person

My diagnosis has made me rethink my identity

My diagnosis has made me think I am crazy

I have felt I will always be stuck with my diagnosis

My diagnosis has made me more reliant on others

Appendix T: Diagnosis Impact Scale Proposed for Clinical Use

The following is a series of items which relate to the possible impact of having a mental health diagnosis. For the purposes of this scale, a mental health ‘diagnosis’ refers to a specific mental

illness label given by a healthcare professional rather than a self-diagnosis or suggestions from friends or loved ones.

Mental illness refers to a wide range of mental health conditions — disorders that affect your mood, thinking, behaviour and overall functioning.

Please bear in mind that the questions are about the impact of the diagnosis, itself, on your life, rather than the effect of your mental health difficulties, per se.

If you have received more than one diagnosis, please answer about the diagnosis which has had the greatest effect on you/feels most important to you.

You are asked to think about how your diagnosis has impacted you since you received it, and based on this, to indicate your level of agreement with each of the statements by circling one of the options below.

1. My diagnosis has been comforting

①	②	③	④	⑤
Strongly agree	Somewhat agree	Neither agree nor disagree	Somewhat disagree	Strongly disagree

2. My diagnosis has made me rethink my identity

①	②	③	④	⑤
Strongly agree	Somewhat agree	Neither agree nor disagree	Somewhat disagree	Strongly disagree

3. My diagnosis has made my difficulties worse

①	②	③	④	⑤
Strongly agree	Somewhat agree	Neither agree nor disagree	Somewhat disagree	Strongly disagree

4. My diagnosis has led to me being happier

①	②	③	④	⑤
Strongly agree	Somewhat agree	Neither agree nor disagree	Somewhat disagree	Strongly disagree

5. My diagnosis has made me more reliant on others

①	②	③	④	⑤
Strongly agree	Somewhat agree	Neither agree nor disagree	Somewhat disagree	Strongly disagree

6. I have felt that my diagnosis defines me

①	②	③	④	⑤
Strongly agree	Somewhat agree	Neither agree nor disagree	Somewhat disagree	Strongly disagree

7. My diagnosis has made me feel my mental health difficulties are taken seriously

①	②	③	④	⑤
Strongly	Somewhat	Neither agree	Somewhat	Strongly

agree	agree	nor disagree	disagree	disagree

8. My diagnosis has helped me to understand myself better

①	②	③	④	⑤
Strongly agree	Somewhat agree	Neither agree nor disagree	Somewhat disagree	Strongly disagree

9. My diagnosis has made me feel more 'normal'

①	②	③	④	⑤
Strongly agree	Somewhat agree	Neither agree nor disagree	Somewhat disagree	Strongly disagree

10. My diagnosis has made me feel I am a weak person

①	②	③	④	⑤
Strongly agree	Somewhat agree	Neither agree nor disagree	Somewhat disagree	Strongly disagree

11. My diagnosis has helped me to feel better about myself

①	②	③	④	⑤
Strongly agree	Somewhat agree	Neither agree nor disagree	Somewhat disagree	Strongly disagree

12. It would have been better if I had not been diagnosed

①	②	③	④	⑤
Strongly agree	Somewhat agree	Neither agree nor disagree	Somewhat disagree	Strongly disagree

13. My diagnosis has given me greater access to professional help

①	②	③	④	⑤
Strongly agree	Somewhat agree	Neither agree nor disagree	Somewhat disagree	Strongly disagree

14. My diagnosis has made me think I am crazy

①	②	③	④	⑤
Strongly agree	Somewhat agree	Neither agree nor disagree	Somewhat disagree	Strongly disagree

15. I have felt I will always be stuck with my diagnosis

①	②	③	④	⑤
Strongly agree	Somewhat agree	Neither agree nor disagree	Somewhat disagree	Strongly disagree

16. Thanks to my diagnosis I have been more willing to seek professional help

①	②	③	④	⑤
Strongly agree	Somewhat agree	Neither agree nor disagree	Somewhat disagree	Strongly disagree

17. My diagnosis has motivated me to find better ways of managing my difficulties

①	②	③	④	⑤
Strongly agree	Somewhat agree	Neither agree nor disagree	Somewhat disagree	Strongly disagree

18. I have felt that my diagnosis means I am a ‘damaged’ person

①	②	③	④	⑤
Strongly agree	Somewhat agree	Neither agree nor disagree	Somewhat disagree	Strongly disagree

19. My diagnosis has given me hope

①	②	③	④	⑤
Strongly agree	Somewhat agree	Neither agree nor disagree	Somewhat disagree	Strongly disagree